

# Palliative care in the region represented by the Middle East Cancer Consortium



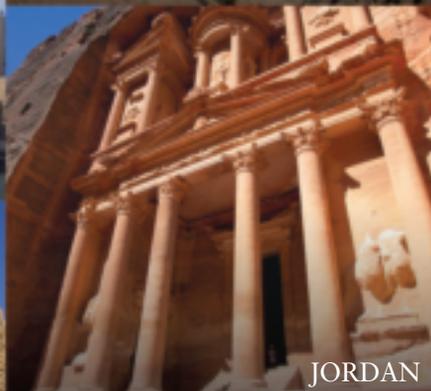
CYPRUS



EGYPT



ISRAEL



JORDAN



PALESTINIAN AUTHORITY



TURKEY



**Palliative Care Developments  
in the Region Represented by  
the Middle East Cancer Consortium:  
A Review and Comparative Analysis**

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Amanda Bingley & David Clark

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# Acknowledgments

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All errors of commission or omission are, of course, our own.

## CITATION

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Citation for a chapter should also include the chapter title.

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## FRONT COVER PICTURES

Cyprus: 7<sup>th</sup> century Byzantine castle in Pathos, ruined by earthquake in 1222

Egypt: Menkaure's Pyramid on Giza Plateau

Jordan: Petra, an impressive façade carved into the rock more than 2000 years ago

Israel: Jaffa Port, a seaport at least 3200 years old

Turkey: Celsus Library in Ephesus, completed in AD 135

Palestinian Authority: Hisham Palace, Jericho (West Bank)



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# Preface

Arguably, the three most important features of cancer in low- and medium-resource settings are “late presentation, late presentation, and late presentation.” The fact that cancer often presents at an advanced stage means that curative therapeutic approaches are less effective and that the need for palliative care is all the more pressing. The Middle East Cancer Consortium ([www.mecc.cancer.gov](http://www.mecc.cancer.gov)) was established in 1996, and its first regional project involved cancer registries that documented not only the incidence of various cancers but also the stage of the disease at diagnosis. MECC’s second regional project revolves around a response to this information aimed at building capacity for palliative care in the region. To do so effectively, it is necessary to establish a baseline of information on palliative care services in the jurisdictions covered by MECC and to examine barriers to delivery of palliative care that might exist. Toward this end the U.S. National Cancer Institute (NCI), a major sponsor of MECC, commissioned the International Observatory on End of Life Care (based at Lancaster University, UK) to conduct the study described in this monograph.

The results of this survey clearly indicate the necessity to expand and improve palliative care services for patients suffering from physical as well as psychosocial and spiritual distress as a result of a cancer diagnosis. While many palliative care services in the region focus on cancer, it is evident that these services can also aid patients with other life-threatening diseases as well. MECC has already begun to address the issue of palliative care by organizing several regional training and educational activities aimed at capacity-building. Moreover, MECC seeks to build a consensus among its members to establish standards for palliative care services in the region. This sort of consensus building has been previously utilized within MECC to develop standards for cancer registry ([www.mecc.cancer.gov/standards.html](http://www.mecc.cancer.gov/standards.html)) that have enabled comparisons of cancer incidence rates in the region as detailed in a previous monograph published by the NCI (1). Despite the difficulties of working in the Middle East, MECC has shown that well-meaning individuals can put

aside political differences and work collectively for the good of all the people in the region.

We applaud the work done by the International Observatory on End of Life Care, and we are confident that it will prove to be a valuable resource for planning and implementing activities in the Middle East aimed to improve palliative care.

Michael Silbermann, M.D., Executive Director, MECC

Joe B. Harford, Ph.D., Director, Office of International Affairs, NCI

## REFERENCE

1. Freedman LS, Edwards BK, Ries LAG, Young JL (eds.) Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) Compared with US SEER. National Cancer Institute, 2006. NIH Pub. No. 06-5873. Bethesda, MD.



# Executive Summary

## MECC Palliative Care Review 2006

Palliative care developments in the region represented by the Middle East Cancer Consortium provides the first comprehensive review and comparative analysis of palliative care in MECC members Cyprus, Egypt, Israel, Jordan, Palestinian Authority, and Turkey. The monograph describes palliative care services both across the region and within individual MECC members in terms of the numbers of patients, coverage, estimated workforce, patient capacity, services per million population, and type and range of services. Specific palliative care service data were collected throughout the year 2005.

The review includes comparative population data and epidemiology. It describes the different health care systems, the funding of general and palliative care services, the availability of opioids, opioid-related legislation, as well as relevant education and training programs. It outlines the common barriers to palliative care service development in the MECC region and lists future plans and goals as identified by key health professionals. All figures relating to socio-demographic and epidemiological data are accurate as of January 2007.

### MAJOR FINDINGS ACROSS THE REGION REPRESENTED BY MECC MEMBERS IN 2005

A total of 69 palliative care services were identified in the region represented by MECC: Cyprus, Egypt, Israel, Jordan, Palestinian Authority, and Turkey, covering a population of 162.9 million.

The primary causes of death across the MECC region are cardio-vascular and heart diseases. Cancer is the second commonest cause of disease-related death. Lung cancer is the commonest in men, breast cancer the commonest in women. Colorectal cancer is the second commonest in both men and women. The highest percentage of cancer deaths per population is found in Israel.

Palliative care provision is estimated at 2.34 services per million people. An average 95% of all palliative care in the region is specifically set up for cancer patients. At a local level, while some MECC members provide care for cancer patients only, in others there is limited provision for patients with other illnesses such as AIDS, heart failure, and neurological conditions. There is very limited pediatric palliative care in Israel and Jordan. No dedicated pediatric services exist elsewhere in the MECC region.

Patient capacity for palliative care is estimated at around 168 inpatient beds in either freestanding hospice units or specialist hospital units and around 653 home care patients at any one time. These figures are subject to fluctuation, depending on funding, health care systems, state of development, and workforce capacity. Israel provides additional home care capacity via an extensive community medicine system.

The estimated palliative care workforce is 434 health professionals. Trained volunteers are active in many services, particularly in not-for-profit home care services. Exact numbers of volunteers are unknown.

Hospice and palliative care service coverage across the region and at a local level is markedly uneven. Cyprus and Israel have the most comprehensive coverage of dedicated palliative care for patients with cancer across significant numbers of their urban and rural populations; in Jordan and Egypt coverage is restricted to those people resident in or able to travel to capital cities with either limited charitable provision or support in specialist cancer centers; in Turkey and the Palestinian Authority, there is limited coverage in a few hospitals in major cities for patients treated in their specialist pain or oncology units; these patients are fortunate to have palliative care trained health professionals.

Funding for palliative care services varies greatly across the region and locally. Israel has the most comprehensive funding: a mix of charitable, government, and insurance

health care systems. Jordan has a similar mix of funding sources. Cyprus relies almost entirely on charitable funding, with government providing small annual subsidies. Egypt has one small charitable funded service; otherwise, as in Turkey and the Palestinian Authority, no dedicated funding sources exist beyond health care systems provided by government, limited private medical insurance, and one or two non-government organizations.

Opioids are available throughout the region. All member governments have passed legislation for the prescription of any appropriate strength of generic or proprietary medication. Quantities permitted per prescription vary from 3 days up to 10 days supply. In Israel physicians may, in exceptional circumstances, prescribe 30 days supply. Opioid phobia leading to inadequate pain and symptom management is a continuing issue throughout the region, despite the introduction of training programs in Israel, Cyprus, and Jordan to educate health professionals, including pharmacists. Turkey has an ongoing publicity program to educate government, health professionals, and the public.

Opioid consumption is highest in Israel and Cyprus, countries with the most developed specialist palliative care services; consumption is relatively low in Egypt, Jordan, and Turkey. The Palestinian Authority has limited and erratic access to a small range of opioid medications. Commonest opioid medications used in palliative care are reported to include codeine, pethidine, and generic morphine preparations. Since 2000 the International Narcotic Control Board records a trend for less prescribing of cheaper generic morphine and instead an increase in the use of more expensive proprietary opioids such as fentanyl, particularly in the form of transdermal patches.

Access to education and training in palliative care varies considerably across the MECC region. Interested health professionals take funding opportunities where possible to access specialist postgraduate programs or short seminars in other countries, particularly the US and UK. International conferences and seminars, including those organized by MECC, have proved supportive. Core training units in palliative care are available for nurses in Cyprus, Israel and Jordan, and for medical students in Israel.

Barriers to palliative care service development are reported as: a lack of core education and training, limited resources with very little secure funding, and inadequate government legislation to include palliative care in the general health care system.

Future plans include: service providers negotiating with governments to improve funding and support the expansion of inpatient and home care hospice services throughout the health care system as well as the introduction of palliative care as a medical specialty, part of core medical and nurs-

ing curricula education, and for all health professionals to have access to postgraduate training in palliative care. Health professionals across the region would also like to see palliative care extend to a greater range of illnesses at the end of life.

# Chapter 1

## Introduction: Background, Aims, & Methods

In this monograph we present a summary, comparative analysis and review of palliative care provision in the geographic region of the Middle East. The review includes a set of complete reports, compiled in 2005, on palliative care services in: Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey.

The reports presented here are the result of a commission originating from the meeting of the Ministerial Steering Committee of the Middle East Cancer Consortium (MECC) held in May 2003 in Geneva. Several representatives expressed their desire to Tommy Thompson, then Secretary of the U.S. Department of Health and Human Services, for an increased emphasis on palliative care in the context of cancer treatment. As a result of this meeting, Secretary Thompson asked the National Cancer Institute (NCI), Bethesda, Maryland, USA, to take the lead in planning a workshop on palliative care to be held in the region. The purpose of the workshop was to raise awareness of the need for palliative care programs and to provide access to international experts in this field. The workshop took place in Larnaca, Cyprus, 2-3 February 2004 for representatives in palliative care from the members of MECC: Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey.

A pilot questionnaire survey of current hospice and palliative care service provision in the region represented by MECC was conducted prior to this meeting during December 2003–January 2004 by the International Observatory on End of Life Care (IOELC). The survey was commissioned by Dr. Joe Harford, Director of the Office of International Affairs of the NCI.

Following the 2004 pilot survey IOELC was commissioned and funded by NCI to write full “country reports” on hospice and palliative care service provision for all the current members of MECC: Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey. The IOELC “global analysis program” aims to map palliative care development, history and current services, country by country, around the world using a common template, which enables

a comparative analysis. Country reports provide a resource for current and future policy, education and training, and service development. All these reports are compiled using a multi-method approach incorporating quantitative and qualitative analysis, including statistical information, questionnaires (see Appendix 1), ethnographic interviews and narrative accounts, referenced peer-reviewed and grey literature and photographs. Interviews are conducted wherever possible in each country with key health care professionals and others involved in service provision (see Appendix 2).

### METHODS OF DATA COLLECTION

The MECC project involved data collection at all the levels outlined above. Meticulous attention was paid to validation and cross-referencing of all information. Building on the pilot study conducted in 2004, we were able to contact a total of 59 individuals in the region covered by MECC, who were interviewed individually or in group settings (including nine telephone interviews). A further nine individuals provided detailed information by email and questionnaires. Interviewees included key palliative care physicians, oncologists, surgeons, specialist nurses, nurses, social workers, psychologists, administrators, spiritual counselors, occupational therapists and volunteers. We visited a total of 14 palliative care units and hospices providing single or multiple services in Cyprus, Israel, Jordan and the Palestinian Authority. The range of services visited included home care, a mobile unit, inpatient hospice, inpatient hospital-based units, and oncology-based support services.

This work was completed in December 2005 with all reports accessible on the IOELC website ([www.eolc-observatory.net](http://www.eolc-observatory.net)). Since posting, there has been a very significant number of “hits” on these reports, together with some extremely favorable comments received from individual colleagues in the region. A second MECC palliative care training meeting took place in Larnaca, Cyprus, 15-17 November 2005 when participants had access to the presentation of findings from the IOELC report.

This monograph contains a comprehensive synthesis of the project's findings furthering the dissemination of MECC reports completed in December 2005. The production and publication of country reports has already been found to have provided an invaluable resource in raising awareness of palliative care issues in the areas represented by MECC. This publication aims to provide a baseline of information suitable for use in education and training, and to facilitate policy and service development.

## STRUCTURE AND CONTENTS OF THE REVIEW

Following this introduction and background to the project, Chapter 2 provides a comprehensive and comparative analysis of palliative care provision across the region represented by MECC. Using additional tables to support our narrative approach we give an overview of the quantity, coverage, range and types of service provision currently operating, patterns of service development, levels of responsiveness of health service providers to palliative care needs and the perceived gaps in service provision. We compare four key issues of health policy and legislation that are considered to be crucial elements in the successful development of palliative care provision in the region: opioid availability, education and training of health care professionals and volunteers, financing of services, and different modes of access to palliative care.

The final part of Chapter 2 focuses on service development from the perspectives of local activists and service providers. The discussion includes how different service providers address specific issues around multicultural needs, pediatric palliative care, and care for patients with diseases other than cancer. We provide a brief overview of the levels of published literature in the region from hospice, palliative care and related sources, including the "grey" literature (newsletters, reports, technical documents), and information from web-based sources. Chapter 2 concludes by identifying some key issues and recommendations identified by researchers and key palliative care professionals in the region. We note major indicators to success as well as describing the most significant obstacles and challenges. Reported future plans are outlined that aim to improve existing services or encourage the development of new services.

Chapter 3 places the region represented by MECC in context giving a sociodemographic overview including population patterns, epidemiology, public health and health care systems. Where possible we use 2004-2006 estimates with further updates accurate as of January 2007, from available data returns by national public health registries

and international organizations. Appendix 3 gives a brief general outline of the region's political and economic situation using various referenced sources providing information up to date at the time of writing.

The remaining chapters (4 to 9) present the six individual reports, compiled in 2005, on palliative care service provision in Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey. Each report uses data collected from site visits, including narrative accounts and "oral histories" from interviews with key professionals, specific population, health care and epidemiological data, and documentary analysis. The reports cover all known individual palliative care and hospice services operational in 2005, and the range and type of provision offered. We include the history of services, locally and nationally, together with any specific plans for future development.

In this context "Middle East" denotes the geographic region and does not necessarily represent any particular political or economic grouping.

## REFERENCES

1. The Middle East Cancer Consortium (MECC) was established in 1996 with the aim of setting up population-based cancer registries for member countries in order to monitor cancer incidence, mortality and epidemiology, promote preventative health policy and encourage research and educational links (Silbermann and Young, 2005; Silbermann, 2001; Freedman et al., 2001).
2. The members of MECC as of July 2005 are Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey. Turkey joined MECC in June 2004. Since 2004 MECC has started an education and training program in palliative care with the aim of supporting the development and improvement of services and links nationally and internationally. <http://mecc.cancer.gov/registry.html>.
3. Clark D, Wright M, Bingley AF. A questionnaire survey on behalf of the National Cancer Institute in preparation for the workshop on Palliative Care in the Middle East: Larnaca, Cyprus: 2 -3 February, 2004, Unpublished report: International Observatory on End of Life Care, Lancaster University, UK.

# Chapter 2

## A Comparative Analysis of Palliative Care Provision in the MECC Region

This chapter offers a comparative analysis of the development of some key aspects of hospice and palliative care provision in the MECC region. We examine the palliative care service provision across the region, including the range and type of current services and patterns of service development, levels of responsiveness of health service providers to palliative care needs, and the perceived gaps in service provision. We compare four aspects of health policy and legislation that are considered crucial elements in the successful development of palliative care provision: opioid availability, education and training of health care professionals and volunteers, financing of services, and modes of access to palliative care. We explore how different service providers address specific issues relating to multicultural needs, pediatric palliative care, older people at the end of life, and care for patients with diseases other than cancer.

The chapter includes a short overview of the range of published literature in the region from hospice, palliative care and related sources, including the “grey” literature (e.g., newsletters, reports, and technical documents) and information from internet-based sources. We conclude by highlighting some key issues and recommendations identified by researchers and key palliative care professionals in the region. We note examples of success as well as the most significant obstacles and challenges. Reported future plans are outlined that aim to improve existing services or encourage the development of new services.

### PALLIATIVE CARE SERVICE PROVISION

In 2005, we identified a total of 69 services across the region that are defined as dedicated to providing supportive

**Table 2.1. Adult and pediatric supportive and palliative care provision in MECC (2005)**

	Adult services									Pediatric services			
	Freestanding unit	Hospital unit	Hospital-based consultation	Home care	Day care	Outpatient clinic	Drop-in center	Mobile unit	NGO support*	Pediatric unit	Pediatric hospital support	Pediatric home care	Total
<b>Cyprus</b>	1	-	-	2	2	2	-	-	3	-	-	-	10
<b>Egypt</b>	2	1	-	1	-	1	-	-	-	-	-	-	5
<b>Israel</b>	3	4	2	7	2	2	1	1	2	1	5	1	31
<b>Jordan</b>	-	1	2	2	-	1	-	-	-	-	1	1	8
<b>Palestinian Authority</b>	-	-	-	-	-	5	-	-	1	-	2	-	8
<b>Turkey</b>	-	-	7	-	-	-	-	-	-	-	-	-	7
<b>Total</b>	<b>6</b>	<b>6</b>	<b>11</b>	<b>12</b>	<b>4</b>	<b>11</b>	<b>1</b>	<b>1</b>	<b>6</b>	<b>1</b>	<b>8</b>	<b>2</b>	<b>69</b>

\*NGO support indicates the presence of organizations which fund or voluntarily provide supportive or palliative care services (this may be the stated sole purpose of the NGO (e.g. Cyprus Anti-Cancer Society) or additional to other more general services in health or social care support offered by the organization (e.g. Patients Friends Society in the Palestinian Authority).

Table 2.2. Typology of stages of palliative care development

“No services identified”	“Capacity building”	“Localized provision”	“Approaching integration”
	<ul style="list-style-type: none"> <li>● Initial awareness of palliative care needs</li> <li>● Expressions of interest registered with key organizations (e.g., MECC, WHO, EAPC)<sup>a</sup></li> <li>● International links established with other hospice-palliative<sup>b</sup> care service providers</li> <li>● Conference participation</li> <li>● Visits to hospice-palliative care organizations</li> <li>● Education and training (visiting teams/ overseas training)</li> <li>● Preparation of development strategy; lobbying of policymakers/ health ministries for palliative care to be part of a National Cancer Control Plan (NCCP)<sup>c</sup></li> </ul>	<ul style="list-style-type: none"> <li>● Initial capacity building<sup>d</sup> activities</li> <li>● Local campaigning and publicity</li> <li>● Services set up – (i.e. home care, or freestanding hospices); funding source established</li> <li>● Government legislation in progress (NCCP to include palliative care)</li> <li>● Opioids available</li> <li>● Training within hospice organization plus external courses</li> <li>● Developing academic links</li> <li>● Developing research activity</li> </ul>	<ul style="list-style-type: none"> <li>● Capacity building and localized activities</li> <li>● Regular campaigning and publicity countrywide</li> <li>● Range of providers and service types</li> <li>● Broad awareness of palliative care needs</li> <li>● Some integration with mainstream health providers</li> <li>● Opioid, NCCP and palliative care health policy/legislation agreed and/ or in statute book</li> <li>● Established education centers</li> <li>● Academic links and development of core curricula for undergraduate and postgraduate health professional training</li> <li>● Research activity – national/ international publications</li> </ul>

Source: Wright and Clark (2006); Wright et al. (2006)

<sup>a</sup> See Appendix 1 for abbreviations

<sup>b</sup> Hospice-palliative is common usage for our publications; see Wright et al. (2006) and reports on IOELC website

<sup>c</sup> NCCPs are part of a package of legislation to ensure government health care provides for cancer prevention and treatment programs – palliative care health professionals lobby their governments to include at most basic provision (at least acknowledgement of need) for palliative care as part of the NCCP – this is part of palliative care development strategy that is encouraged by WHO, EAPC and other supportive international organizations.

<sup>d</sup> Capacity building does not have a hyphen in the original IOELC tables

care or palliative care (Table 2.1). Details of these services appear in Chapters 4-9.

Where a service is in the process of development from (largely) physical care--pain and symptom management--to a broader form of holistic care that approximates the World Health Organization (WHO) definition of palliative care, we have included it in our analysis (1). For example, we include services where, although there is no specialist provision, health care professionals undertake palliative care training, raise professional awareness of needs and practices, and, in some cases, are starting to actively develop training opportunities in existing oncology clinic, hospital units, or nongovernment organizations (NGOs).

In describing the current state of hospice and palliative care service provision, we apply a typology that defines different stages of development. Four categories are used: “no services identified,” “capacity building,” “localized provision,” and “approaching integration.” These are fully defined in Table 2.2 (2).

The map in Figure 2.1 shows the four categories applied across the MECC region according to the status, range, and type of provision identified in each country and area.

The Palestinian Authority and Turkey are described as in the initial stage of palliative care development, where there is no specialist service provision, although there are interested health care professionals in the process of “capacity building,” raising awareness, and, as far as possible, introducing palliative care practice into their work. Jordan and Egypt are identified as providing localized provision, where individual local services and organizations are established or in development, and some training is available for professionals, but other key aspects are still in the process of debate or development, such as a national strategy for provision, opioid policy, and education. Cyprus and Israel are approaching integration because they have organizations with well-established services, in some cases integral to existing health care providers, national policies on opioid availability, education, and training (undergraduate and postgraduate education in Israel, and training at professional levels in both Israel and Cyprus), and there is clear evidence of clinical and academic research activity.

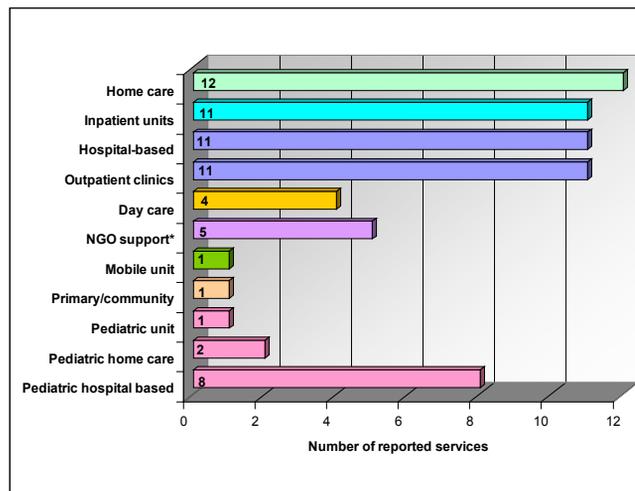
Figure 2.1. Map of MECC region showing different levels of service development according to typology defined as “capacity building” (blue: Palestinian Authority, Turkey), “localized provision” (green: Egypt, Jordan), and “approaching integration” (yellow: Cyprus, Israel)



### PALLIATIVE CARE COVERAGE IN THE MECC REGION

There is enormous variation in palliative care provision and patterns of development in the region represented by MECC (Figure 2.2). Currently, home care services are the most common type of service provision, but there is no home care in Egypt, the Palestinian Authority, or Turkey. In many cases, home care services are initially set up by volunteers; in almost all situations, these are trained nurses, social workers, and physicians working in their own time. Later, the services are taken on and supported by an NGO or existing health care provider. For example, one home care service in Israel was originally established by a group of untrained volunteers who responded to the needs of people in their community dying of cancer. The volunteers organized a group of trained professionals and supportive volunteers, who are trained in basic psychosocial and personal support skills.

Figure 2.2. Range of different types of supportive and palliative care in the MECC region (2005)



\*NGO support includes charities entirely dedicated to palliative care and also organizations that offer specific support at the end of life as part of other humanitarian work.

In Cyprus, two charities provide all the specialist services in the Greek Cypriot south, and one provides some limited support in the Turkish Cypriot north of the island. In Israel, one major NGO provides funding toward several palliative and supportive end-of-life care services, for educational and research activity, clinical development and public health education programs. In the Palestinian Authority, one NGO will offer psycho-social support for women with breast cancer at the end of life, and also provides a range of supportive services for breast cancer

Illustration 2.1 A freestanding hospice, the Ina and Jack Kaye Hospice at Hadassah Mount Scopus, Jerusalem provides inpatient and home care services [photograph: Amanda Bingley, May 2005]





**Illustration 2.2** The Cairo Evangelical Medical Hospice in Egypt is one of 2 privately funded services with a small inpatient unit and outpatient service for people with cancer at the end of life [photograph kind permission of Dr. Naguib Elnikhaily, March 2005]

survivors, and other health-related services. Of the 11 hospice inpatient units in the region, 7 are freestanding (1 unit in Cyprus, 2 in Egypt, and 4 in Israel).

There are four specialist units with beds for palliative care patients based within hospital oncology wards in Israel and Jordan. These kinds of specialist units are distinct from hospital-based consultation offered at the end of life. In such situations, professionals who are aware of the principles of palliative medicine or who have completed some specialist training are providing pain and symptom management. However, they are often constrained from developing full palliative care services because of limited or no resources, a lack of trained staff, and perhaps little or no support from colleagues. In 2005, this kind of hospital-based consultation was the only palliative care service available in Turkey, although a few dedicated oncologists are working to develop more comprehensive services in several major hospitals. In the Palestinian Authority and Egypt, this kind of service continues to be the main type provided.

There is a major lack of pediatric palliative care support across the region, with only a single small four-bed unit dedicated to palliative care for children found in Israel and two home care services that will care for children if requested, in Israel. Similarly in Jordan one home care service will care for children on request, although in both Israel and Jordan the services are primarily for adults. There are hospital-based consultation and support ser-

vices in major pediatric cancer units in Jordan and the Palestinian Authority. In Israel, there are some specialist palliative care consultation services in major pediatric hospital units, and currently the only services that are fully developed and offering a range of psycho-social support including bereavement services are in Israel. In part, as the quote below illustrates, this reflects the different approaches to, and needs of, children with life-limiting illness, where both professionals and family will continue to pursue active treatment right up to the end of life and there is often anxiety at the prospect of hospice care, which is seen as “giving up” hope (3).

“In a country like Israel, very little palliative care is done for children: they fight until the very end in terms of active treatment. And they feel a lot of confidence in the hospitals. We had two that we took care of (of course it’s very traumatic for the staff too), but basically their main umbilical cord remains the hospital. In other words, even when their child is dying, if there’s any chance that some new type of treatment will [work]...they can see the oncologist again and have one more treatment. We don’t get into the stage that they say no more treatment.” Home hospice team physicians in discussion – Israel, May 2005 (4).

In Cyprus there are similar difficulties in pediatric services in terms of access to appropriate pain relief and the fact that opioids for children are generally given as IV infusions in hospital. As the quote below suggests this may ultimately result in limited choice for a family around the preferred place of care for their child at the end of life:

“[In Cyprus]...with the pediatric oncologist, I always send him copies of anything that comes through, especially related to opioids or pain in children. They do use morphine with children. But children don’t really die at home, they tend to be admitted to the ward and given IV fluids with morphine. At least they are using morphine now for the children, which is a move forward.” Clinical nurse specialist – Cyprus 2005 (5).

Another area of service provision that is a concern for professionals across MECC is the severe lack of palliative care services for patients with cardiovascular disease, despite the overwhelming numbers of deaths from these causes. Only two countries (Israel and Jordan) have hospice and palliative care provision (one service in Jordan and two in Israel) for patients with diseases other than cancer, despite the proven benefits of palliative care, for example, in patients with heart failure (6). The lack of services to support end-of-life care in people with non-cancer-related disease is in stark contrast to the response

**Table 2.3. Palliative and supportive care capacity\* in the MECC region reported estimates 2005**

	Beds in freestanding or inpatient units	Home hospice capacity (maximum)
Cyprus	18 (+ 40 hospital-based)	121 per month
Egypt	9	-
Israel	93	498 (at any one time)
Jordan	8	34 (at any one time)
Palestinian Authority	-	-
Turkey	-	-
<b>Total capacity</b>	<b>168</b>	<b>653</b>

\*Freestanding units are purpose built hospices. Capacity means total bed numbers in the hospice. Inpatient unit capacity means bed numbers in an inpatient hospital-based unit – i.e. beds may be within an oncology unit – it is not unusual for bed numbers to vary – for example a hospital might be forced in an emergency to use a palliative care bed for an oncology patient or a patient from a different unit – hence the estimates. Home hospice capacity means the numbers of patients that can be cared for at any one time – this will depend on staffing levels – the figures for all these designations were stated as estimates within a fairly stable range – for example a home hospice will be staffed according to the level of funding available and often also depends on how many hours the director and/or team feel they can manage to work, if they are voluntary workers or part funded. Thus, they may be set up to care for between 20 – 25 patients at any one time. Estimates are based on the maximum numbers given by directors for their hospice.

in some African countries to the overwhelming palliative care needs of very high numbers of people dying from AIDS (7). An estimated 95% of hospice and palliative care in Israel and Jordan is dedicated to cancer patients (8). In Cyprus, Egypt, and Turkey, virtually all of current hospice and palliative care provision is for cancer patients, although Cyprus does have a ward in one hospital for AIDS patients (9).

## PALLIATIVE CARE CAPACITY IN THE MECC REGION

The 69 palliative care services identified in this review cover a total MECC population of 162.9 million people. There is an estimated 2.36 services per million population.

There are insufficient data available to assess the exact palliative care capacity across MECC, but Table 2.3 provides estimates of inpatient beds available in specialist palliative care units, in freestanding units, and in specialist hospital-based units (figures for capacity in general hospital facilities are not known), and some indication of home care service capacity. In addition to an estimated

**Table 2.4. Palliative care workforce capacity in the MECC region: reported estimates in 2005**

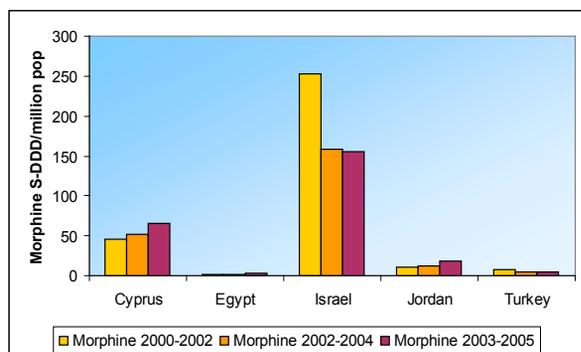
Role in palliative care	Estimated workforce employed full- or part-time
Administrative staff/director	34
Physician/medical director	92
Nurse	230
Social worker	33
Psychologist	17
Physiotherapist	8
Occupational therapist	4
Music therapist/art therapist/ yoga therapist/massage therapist/ dietician	2 / 3 / 1/3 / 3
Spiritual counselor	4
<b>Total</b>	<b>434</b>

168 beds in freestanding or specialist hospital units, there is an estimated 653-patient home care patient capacity at any one time. These figures can fluctuate considerably over a year. In Israel, where there is a community medicine system, an estimated 80 specialist nurses work with around 500 oncology nurses, caring for patients in the home. Jordan is in the process of developing a community medical service.



**Illustration 2.3 Music thanatologist Adira (right) with Shosha**  
[photograph kind permission of the team at the Nancy Caroline Hospice of the Upper Galilee, Israel]

**Figure 2.3. INCB recorded average standard defined daily doses (S-DDD) of morphine per million inhabitants, compared over the years 2002-2005, in Cyprus, Egypt, Israel, Jordan, and Turkey**



Source: International Narcotics Control Board Narcotic Drugs: Estimated World Requirements for 2005. Statistics for 2004. New York: United Nations, 2005.  
Estimated World Requirements for 2007. Statistics for 2005. New York: United Nations, 2006.

## PALLIATIVE CARE WORKFORCE CAPACITY

An estimated 434 health care professionals were actively employed in specialist palliative care in the 69 identified services in the MECC region in 2005. Table 2.4 details their roles and numbers.

Nurses represent the largest number of professionals in palliative care services throughout the MECC region. Many services--for example in Cyprus, Israel, and Jordan--have been set up and run by nurses, with part-time, voluntary support from primary care physicians or oncologists. Often services survived in this way for many years before additional funds supported an expansion of services into teams including full- or part-time social workers and administrators, and later, psychologists. Relatively fewer physiotherapists and occupational therapists participate, and they are more often found in better resourced, well-established services (although several services reported having external access to physiotherapy or occupational therapy support on request). The smallest numbers of the workforce are those professionals offering specialized therapeutics such as music and art therapy, yoga or massage therapy, dietetic advice, and spiritual counseling.

These specialist professionals are only found in around four services in the MECC region; in some cases they are only temporarily in post. One or two services had a particular emphasis on providing this kind of support. In many services, however, the emphasis tends to be on

providing nursing and medical support, either by choice because of the health care providers' focus, or because poor resources or less specialist training limit the extent and range of provision.

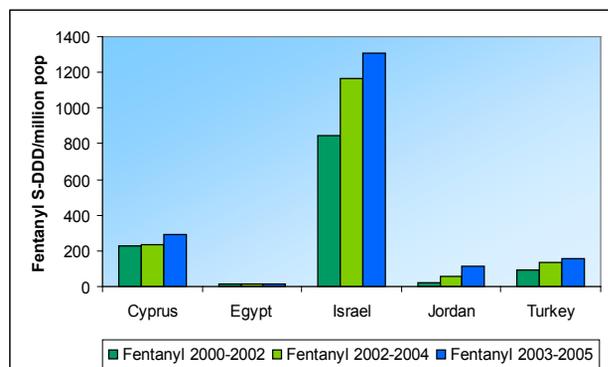
Opioids are reported to be available in all MECC countries across the region. Cyprus, Egypt, Israel, Jordan, and Turkey report annually on opioid preparation and consumption, as sovereign states and members of the International Narcotics Control Board (INCB). Quantities are measured in kilograms or grams per year and are also defined by the INCB as the "average consumption of narcotic drugs, in defined daily doses for statistical purposes per million inhabitants per day" or "average standard defined daily doses (SDDD)." The Palestinian Authority is not an acceded party to the conventions of the INCB, which therefore has no published figures for the consumption of narcotic drugs in the West Bank and Gaza Strip. A limited range of opioids is available for use in oncology units in these areas, although choice and availability of drugs and availability of the different drug dosages cannot be guaranteed (see Chapter 8) (10).

The range of available drugs varies in different countries, but all MECC members report access and usage of common generic opioids used in palliative care: codeine, pethidine, and generic morphine preparations. Health care professionals across the region note a general trend in all pain management, including palliative care, towards an increased use of more expensive proprietary opioids, in particular the fentanyl formulation prescribed as Durogesic (most frequently in the form of transdermal patches). In Israel and Turkey there is a reported reduction in prescriptions of generic morphine (see Figure 2.3 for comparative changes in morphine use from 2000-2005).

In Cyprus, Egypt, and Jordan a marginal increase in morphine use partly reflects a greater overall use of opioids in pain management as well as encouragement to access the cheaper generic opioids. For example in Jordan, since 2004, a local pharmaceutical company has been licensed to produce the cheaper, generic morphine sulphate for use within the country and for export around the region. However, despite this situation, as Figure 2.4 illustrates, from 2000 to 2005 the INCB reports a relatively marked annual increase in fentanyl use in all countries.

In Israel, physicians also note an increased use of other opioid derivatives such as hydrocodone and the synthetic opioid oxycodone. This pattern of increased use of proprietary opioids and derivatives is thought to arise from two key factors. The first is opioid phobia, when the physician, patient, and patient's relatives are anxious about prescriptions of morphine but less concerned when

**Figure 2.4. INCB recorded average standard defined daily doses (S-DDD) of fentanyl per million inhabitants, compared over the years 2002-2005, in Cyprus, Egypt, Israel, Jordan, and Turkey.**



Source: International Narcotics Control Board Narcotic Drugs: Estimated World Requirements for 2005. Statistics for 2004. New York: United Nations, 2005.  
Estimated World Requirements for 2007. Statistics for 2005. New York: United Nations, 2006.

the prescription name does not indicate the opioid nature of the medication. The second factor is that pharmaceutical companies favor marketing profitable proprietary medications. Cheap generic morphine salts, although effective, are considerably less profitable.

MECC members Cyprus, Egypt, Israel, Turkey and the Palestinian Authority all have some form of government legislation for opioid availability and prescribing powers for physicians. Jordan currently has temporary regulations to permit opioid prescribing. Quantities permitted per prescription across the region range from sufficient medication (of any appropriate strength) for a three-day up to a 10-day supply. In Israel, the maximum, and exception, at any one time is a 30-day supply. As part of opioid awareness and education, Israel, Cyprus, and Jordan routinely include pharmacists in their training courses. The increase in training opportunities in Israel and Cyprus has resulted in markedly less antagonism and phobia from health care professionals and, consequently, their patients. Widespread opioid phobia, however, remains a considerable barrier to adequate opioid prescribing in Turkey, and is a continuing problem in Jordan, despite new training programs since 2004.

Lack of training, particularly at the primary and community care level, still leads to inadequate or inappropriate prescribing even in countries “approaching integration” with their palliative care services. The following quote

illustrates the continuing lack of adequate pain management and symptom relief in general health services:

“We encounter problems with two types of physicians ... and I’m generalizing ... One type is physicians who just back away from any involvement with cancer patients, including referring them to us. For a long time, and probably still in areas that are under-served, people just don’t get treated properly. They don’t get treated by the hospital and they don’t get treated by the family physicians properly. ... The other category is the sort of proud family physician; he knows his stuff and thinks that he can handle it, when today really palliative care is different than it was 15 years ago. It’s far more complex ... the drug regimens are more complex and the orientation is far more sophisticated than it was before.” Senior palliative care physician (Israel, 2005) (11).

However, this situation is also reported as having steadily improved from the early 1990s, largely as a result of concerted campaigning by pioneers of palliative care to change government policy and legislation around opioid availability (12). In Turkey, however, Oguz et al. (2003) as cited below, emphasize the ongoing problem in general hospitals, where there is little or no awareness of palliative care needs:

“Narcotics are often available to meet the needs of dying patients with chronic pain, [but] many private pharmacies shun the bureaucracy and the potential liability that goes with dispensing ‘green’ prescriptions (for addictive or abusable [sic] drugs) and ‘red’ prescriptions (for narcotics). The difficulty in finding a health care professional to come to the home to dispense, administer, monitor, or instruct in the proper use of opiates encumbers or entirely obstructs home care with narcotics. Undertreated pain and the lack of a means to secure access to opiates lead people to seek overloaded hospital based clinics or avoidable and costly inpatient treatment. Hospitals and their staff are not organized or trained to provide palliative care.”

Of seven university hospitals and nine state hospitals in the three largest cities Oguz et al. observed that:

“...no hospital had a policy on end of life care, pain management or DNR (do not resuscitate) orders. Dying patients are often placed in what health care professionals informally call ‘agonal rooms.’ These are often in less noticed areas of the hospitals... The dying person is often alone in an institution from which he or she or relatives sought help” (13).

The pattern of inadequate pain and symptom management due to lack of specialist training and awareness is echoed

Table 2.5. Overview of education and training in the MECC region, 2005

	Core education		National specialist education and training		International education/ links	Research activity
	Physicians	Nurses	Diploma/MSc/ CME/ Specialist courses	Short units/ seminar	Fellowships/ diplomas/MSc/ Spec. courses	Journals/ conference
Cyprus		Short placement <sup>a</sup>		Yes	Yes	Yes
Egypt		Unit in development			Yes	
Israel	Yes: unit in 5 <sup>th</sup> yr <sup>b</sup>	Yes	Yes	Yes	Yes	Yes
Jordan		Short placement		Yes	Yes	
Palestinian Authority					Yes	
Turkey				Yes	Yes	Yes
Total <sup>c</sup>	1/6	4/6	1/6	4/6	6/6	3/6

<sup>a</sup> Short placements: nurses spend a short time from a few days, to weeks or perhaps up to 3 months in a hospice as part of their final year or as an optional unit.

<sup>b</sup> Unit of study in 5<sup>th</sup> year.

<sup>c</sup> The totals describe the number of countries with education and training out of the total MECC members: this provides a quick comparative measure of the level of education in the region.

by hospice and palliative care professionals throughout the region.

## EDUCATION AND TRAINING

Education and training in palliative care is available internationally at the postgraduate and fellowship levels for all health care professionals in the MECC region who have the means to travel or who are supported through NGO or other charitable funding. Table 2.5 outlines the available courses and types of training in Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey.

Israel, with the most extensive palliative care services, is the only MECC country that has some core training units in palliative care for medical students and has also developed a national specialist postgraduate qualification in palliative care. Cyprus, Israel, and Jordan provide single units on palliative care during core nursing training. Egypt has some palliative care training in development for core nursing education.

Illustration 2.4 MECC delegates at the first palliative care seminar, Larnaca, Cyprus, February 2-3, 2004.

[photograph: David Clark]



International opportunities in palliative care education are a vital part of raising awareness and providing access to training courses for all MECC members. In the case of physicians in the Palestinian Authority and Egypt, such opportunities represent the only viable training option. The MECC palliative care seminars (the first two of which ran in February 2004 and November 2005) have proved to be an important point of contact and networking for members. In particular, they provide a supportive and collegial environment for professionals who have little chance to develop palliative care skills within their own institutions.

Volunteer support services exist in Cyprus and Israel, and to a limited extent in Jordan and the Palestinian Authority. In all situations where volunteers are involved in a service, some basic training and needs awareness are provided, and this often extends, where possible, to training of family members.

## ETHICAL ISSUES

Issues of disclosure about a patient's prognosis are reported to be a major problem throughout the MECC region. Professionals in Israel and Cyprus, both countries with the most active and extensive palliative care services, note a great improvement in the willingness of health care professionals to be open: a change that has reportedly come about as cancer survival rates improve. Most palliative care professionals are sensitive to their patients' cultural and spiritual differences and many freestanding hospices and home hospices in the MECC region support

### Illustration 2.5 Negev Palliative Care Services “Desert Mobile Unit,” visiting a home care patient near Beersheba, Israel.

[photograph: Amanda Bingley, May 2005]



their patients spiritually, where appropriate. In Israel there is a spiritual counseling training program.

Health care professionals noted often significant inequalities for patients needing access to services. Problems are deemed as particularly acute where community or primary health care awareness is inadequate. Professionals describe situations where a lack of awareness of palliative care needs in the general health care system leads to unnecessary suffering. For example, remote rural areas almost always lack services, with some exceptions in Israel, which has relatively comprehensive community health services, including oncology nurses who are educated in basic palliative care. Jordan is addressing the problem by training professionals who are already working within the relatively new community health care system introduced in the early 2000s.

Military conflict is another problem that poses significant ethical issues. In the Palestinian Authority, the Israeli/Palestinian conflict results in severe difficulties for patients attempting to access services. A positive aspect of the development of palliative care services is the potential to work together in the humanitarian effort to support all communities in the region. For example, the value of sharing experience and building bridges across communities, even those in conflict, is illustrated by this quote:

“They [gave] me the money to open the hospice in the Arab city of Nazareth, and then I was in [the] United States with an Arab social worker, and she was working for the hospice here, and we did some projects together

### Illustration 2.6 Bedouin Arab settlement in the Negev Desert, southern Israel. Palliative care is provided to this community via the Negev Palliative Care Services “Mobile Desert Unit.”

[photograph: Amanda Bingley, May 2005]



with the community of Israel and [the] United States... Sometimes when you are talking about mutual issues that are important for both communities, you are not talking about peace but things that improve peace and understanding, because, you see, we are people the same.” Hospice director, Israel, May 2005 (14).

Another area of ethical concern across the region is the problem of insecure funding. Many palliative care providers are not-for-profit organizations relying on donations. This kind of funding, although limited, may be reasonably stable if fundraising is well managed and supported by regular donors. In Israel, Cyprus, and to a small extent Jordan, some organizations have their income supplemented by a varying percentage of health system funds. Where the services are wholly dependent on government or insurer health care systems, resources are vulnerable to political or economic shifts, particularly if there is insufficient awareness about palliative care needs. In some cases, government or insurer funds have been withdrawn or reduced with little warning, leaving services collapsing or severely cut back, with consequent stress on the general health care service, patients, families, and the workforce. Organizations and individuals involved in palliative care provision see the raising of public and government awareness as a crucial factor in improving this situation and in encouraging a more stable funding policy. Many professionals echo the concern that lack of awareness of the needs for palliative care leads to considerable unrelieved pain and suffering at the end of life for patients with cancer and other life-limiting illnesses, as this quote suggests:

“I’m a person who works in darkness, because I do realize that in this part of the world what is being said in conferences, what is being said under lights, does not really reflect the reality. There are closed homes, there are people who are suffering, and whoever reaches those people will exactly know the value of palliative care.” Hospice director, Jordan, May 2005 (15).

Finally, important ethical issues arise from opioid phobia and lack of training in prescribing opioids, which results in often inadequate pain and symptom management.

## REVIEW OF RANGE AND TYPE OF PUBLISHED MATERIAL RELATING TO PALLIATIVE CARE

Only one MECC member country, Israel, has any consistent and dedicated research activity regarding palliative care (see Chapter 6). Consequently, Israel has the largest number and range of publications specifically on

this topic, as well as an impressive record of publication in international peer-reviewed journals reporting on wide-ranging clinical, psychosocial, cultural, and social science research.

Cyprus is the only other MECC member that produces specialist palliative care literature, although it is very limited (see Chapter 4). Cyprus has the disadvantage of being a small island with no higher education institutions. Consequently, only a handful of health care academics and clinicians have international links and are able to publish in international peer-reviewed journals.

The Palestinian Authority has a small amount of public health literature and a very limited “grey” literature in palliative care (see Chapter 8). Health care professionals in Turkey and Egypt have focused on cancer treatment and pain control, and both countries have a relatively wide range of cancer treatment and pain management literature, some published in international journals. Egypt has virtually no literature on specialist palliative care pain and symptom management (see Chapter 5). In Turkey there is relatively extensive national literature on pain management and a small amount of international medical ethics literature (see Chapter 9).

## BARRIERS TO DEVELOPMENT AND FUTURE PLANS

In this concluding section, we outline key barriers to the development of palliative care and hospice services, as identified by health care professionals across the MECC region. These barriers include a lack of the following: training, resources, relevant government legislation, and secure funding. Future plans are outlined that aim to address these problems, in order to develop and improve palliative care services.

In Cyprus, there are moves by health professionals from the two palliative care NGOs to negotiate with the Ministry of Health to have palliative care integrated into general health services accessible throughout the health care system. Palliative care professionals have a long-term aim to treat patients with cancer as well as those with other illnesses at the end of life.

In Egypt, there is an urgent need to develop basic palliative care training and education. The only two freestanding hospice services are based in the private sector. A small group of health care professionals based in governmental health services aim to develop palliative care that would be accessible throughout the health care system, built

ing on hospital oncology units' existing role in pain and symptom management.

In Israel, the aim is to expand the number and scope of existing services and to treat a greater range of illnesses. Palliative care specialists are negotiating with health insurance companies to cover palliative care as part of the “basket of services.” This coverage would secure financial resources and encourage the development of service provision. There is great pressure on medical education to make palliative care a medical specialty and add it to core curricula in medical schools; it is already part of standard nurse training in Israel. There are also continuing efforts to increase opportunities for postgraduate and professional specialist palliative care training.

In Jordan, the aim is to expand both home care services and specialist inpatient units. By encouraging education and training for community and hospital-based health care professionals educators aim to support the development of palliative care in community services and oncology units. Jordan is actively using support offered by the World Health Organization and the Jordanian Royal Court to develop effective training programs and government legislation.

In the Palestinian Authority, there is a need to raise awareness of palliative care at the government level. However, without international efforts the ongoing conflict draws potential resources away from palliative care. It is hoped that international support will increase to aid the development of palliative care education, training, and services. However, given the problems of access in Gaza and the West Bank, there is a need to ensure flexible service provision.

In Turkey, there are concerted efforts in several university hospitals and one military hospital to develop specialist palliative care training and education. Health care professionals are actively working to develop an inpatient hospice and new home care services. The aim is to broaden hospital-based services to move beyond supportive care and start to provide multidisciplinary approaches to palliative care. Turkish pain specialists continue to raise professional, government, and public awareness of the importance of opioid medication in palliative care.

## CONCLUSION

Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey have very different palliative care needs and are at various stages of palliative care service development. Israel is “approaching integration” in palliative care services and has the most advanced development.

Cyprus is also “approaching integration” but is disadvantaged by the absence of higher education institutions on the island, limiting access to academic and clinical research (Cypriot medical students have to seek their undergraduate education abroad).

Jordan and Egypt have some “localized provision,” but this is more developed in Jordan than in Egypt, where there are very few specialist palliative care services; all state-funded services are still at the level of “capacity building” and the focus is on pain and symptom management. The Palestinian Authority and Turkey are at the point of “capacity building.” However, the Palestinian Authority, at the time of writing, has no resources for service development and struggles to find sufficient resources to provide basic pain and symptom management. In contrast, Turkey is currently witnessing an increase in awareness about the need for specialist palliative care services; Turkish oncologists and pain specialists are active in the palliative care service development within existing pain clinics and oncology units.

The following chapter provides a detailed overview of population patterns, levels of human development, health care systems and epidemiology in Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey.

## ENDNOTES

1. WHO definition and criteria, accessed 3 January 2008 at [www.who.int/cancer/palliative.en](http://www.who.int/cancer/palliative.en): “Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient’s illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”
2. Typology developed by: Wright M and Clark D. Hospice and palliative care in Africa: a review of developments and

- challenges, Oxford: Oxford University Press, 2006. See also Wright M, Wood J, Lynch T, Clark D. Mapping levels of palliative care development: a global view, International Observatory on End of Life Care, Lancaster University, UK with Help the Hospices, UK and NHPCO, USA, 2006.
3. For full discussion of these issues see comments by professionals in Cyprus (Chapter 4), Israel (Chapter 6), Jordan (Chapter 7) and the Palestinian Authority (Chapter 8).
  4. IOELC interview: Dr. Jim Shalom, Dr. Eyal Goldberger, Specialist Nurse: Yael Bleich and Social Worker: Yaniv Ben-Shoshan, (Nancy Caroline Hospice of the Upper Galilee, HUG) – 9 May 2005.
  5. IOELC interview: Clinical nurse specialist at PA.SY.KAF, Jane Kakas - 8 April 2005.
  6. See Ward C. The need for palliative care in the management of heart failure, *Heart* 2002;87:294-298 [heart.bmjournals.com](http://heart.bmjournals.com) accessed 19 October 2006.
  7. Wright M and Clark D. Hospice and palliative care in Africa: a review of developments and challenges, Oxford: Oxford University Press, 2006.
  8. See details of specific services outlined in Chapter 6 (Israel) and Chapter 7 (Jordan).
  9. See details of specific services outlined in Chapter 4, Cyprus; Chapter 5, Egypt; Chapter 8, Palestinian Authority; and Chapter 9, Turkey.
  10. 2006 data on access and availability of medications in Gaza and the West Bank can be found on the WHO Health Crisis in Action Report, July 2006. See updated information on the WHO weblink [millenniumindicators.un.org/unsd/mi/mi\\_results](http://millenniumindicators.un.org/unsd/mi/mi_results).
  11. Dr. Jim Shalom in IOELC interview: with team members Dr. Eyal Goldberger, Yael Bleich and Yaniv Ben-Shoshan, at Nancy Caroline Hospice of the Upper Galilee (HUG) – 9 May 2005.
  12. IOELC interviews: Dr. Alexander Waller, Tel Hashomer, Tel Aviv – 8 May 2005; Dr. Nathan Cherny, Sha'are Zedek, Jerusalem – 4 May 2005; Dr. Amitai Oberman, Home Hospice in the Valleys, Nazareth – 10 May 2005.
  13. Oguz NY, Miles SH, Buken N, Civaner M. End of life care in Turkey, *Cambridge Quarterly of Healthcare Ethics*, 2003;12, 279-284.
  14. IOELC interview: Mali Szlaifer, Home Hospice of the Valleys, Nazareth - 8 May 2005.
  15. IOELC interview: Rana Hammad – 12 May 2005.

# Chapter 3

## The MECC Region in Context: Socio-Demography, Health Care Systems, Epidemiology, and Public Health

This chapter outlines and compares the socio-demographic context within which MECC members aim to support the development of hospice and palliative care services. The first part of the chapter describes population patterns, including density, distribution, age structure, and human development indicators (see also detailed statistical data in Freedman et al., 2006) (1). We also examine and compare the different health care systems across the region, and provide an overview of relevant epidemiological and public health issues. For a summary of the political economy in the region, see Appendix 3.

### POPULATION PATTERNS

The region represented by MECC members (Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey) encompasses significantly different geographical areas, as shown by the map in Figure 3.1, with vastly differing population size (Table 3.1), density, and distribution (Figure 3.2).

Turkey and Egypt are the two largest MECC members and have the highest populations. Egypt is the second most populous country in the African continent (2), with terrain that is mostly uninhabitable desert. Almost the entire population lives along the Nile River Valley, in the capital Cairo, and around the delta in the coastal cities of Alexandria and Port Said; over half live in densely peopled urban areas (3). Turkey has the largest land area, and in contrast to Egypt, all but the most mountainous areas are habitable. There has been a marked migration of people from rural to urban centers in Turkey. In 1960, 70% of the population lived in rural areas and 30% in urban areas. By 2000, only 25% were living in rural areas and 75% in urban areas, the majority migrating from eastern areas to western areas into the three largest cities: Istanbul, Ankara, and Izmir (4,5).



**Fig 3.1. Map showing region represented by MECC members: Cyprus, Egypt, Israel, Jordan, occupied Palestinian territories (West Bank and Gaza Strip), and Turkey**

Cyprus has the smallest population of the MECC members (6). Many parts of the island are mountainous with rugged terrain, but the populations of Greek Cypriots in the south and Turkish Cypriots in the north are widely distributed

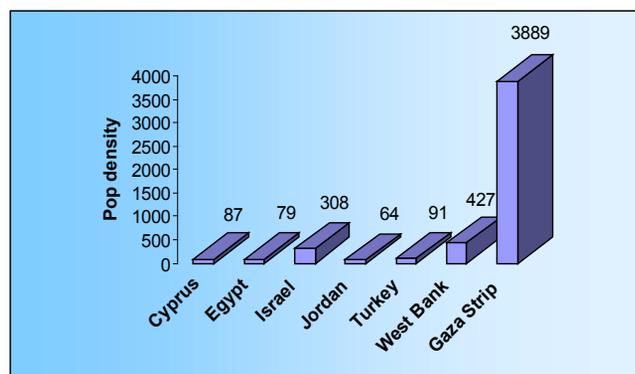
**Table 3.1. Population estimates and life expectancy at birth in the MECC region, 2004**

	Population (millions) <sup>a</sup>	Life expectancy at birth (years)	
		Male	Female
Cyprus	0.8	77	82
Egypt	72.6	66	70
Israel	6.7	78	82
Jordan	5.7	69	73
Palestinian Authority <sup>b</sup>	3.9	71	74
Turkey	73.2	69	73

<sup>a</sup> Source WHO Statistics (data from 2004 returns) (2006 Report) [www.who.int/country/en](http://www.who.int/country/en).

<sup>b</sup> Source WHO Health Action in Crisis Report July 2006 [http://millenniumindicators.un.org/unsd/mi/mi\\_results.asp?crid=275&fid=5](http://millenniumindicators.un.org/unsd/mi/mi_results.asp?crid=275&fid=5).

**Figure 3.2. Comparative population densities (population/km<sup>2</sup>) in the individual countries and areas in the region represented by MECC 2006**



Source: World Factbook (UN returned data) July 2006

in rural areas and the urbanized coastal plains. Around a quarter of the Greek Cypriots live in the divided capital, Nicosia.

Jordan, like Egypt, is largely a desert country, with a mountainous northwest region. The majority of the population (around 90%) lives in semi-urban and urban areas; 63% of these live in the central region of Jordan in the capital city Amman and in smaller regional areas of Zarqa, Balqa, and Madaba (7). Around 10% of the population is nomadic groups inhabiting desert areas (8).

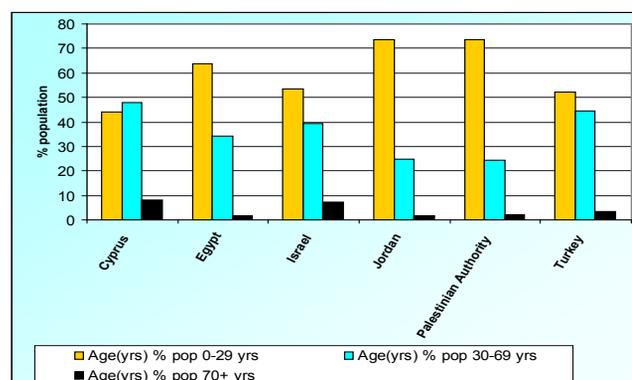
Israel and the Palestinian Authority have the most densely concentrated urban populations in the MECC region. Israel is a relatively small country; about half of its land area to the south is a sparsely populated desert. The vast majority of the population (around 91%) lives in the urbanized upland areas in central and northern Israel, and along the

western coastal plains--mostly in the large metropolitan areas in and around Tel Aviv and Jerusalem, and in the northern port of Haifa (9,10). The Palestinian Authority in the West Bank and the Gaza Strip are densely populated, urbanized areas in semi-arid terrain. Gaza is a narrow strip of coastal land, with the highest population centers located in Gaza City in the north, Khan Yunis in the central area, and Rafah near the southern border. The West Bank is a small, semi-arid, landlocked area to the west of the River Jordan. The majority of the population is urban, living in the larger settlements and camps running north to south from Ramallah, East Jerusalem, and Bethlehem to Nablus and Hebron (11).



**Illustration 3.1. View from East Jerusalem toward Beit Jala and Bethlehem in the West Bank, Palestinian Authority, May 2005.**  
[photograph: Amanda Bingley]

**Figure 3.3. Age range (years) as a percentage of the population in the MECC region, 1998-2001\***



\*2001 estimates for Cyprus, Israel and Egypt; 1999 estimates for Jordan; 1998 estimates for Palestinian Authority and Turkey.

Source: [http://mecc.cancer.gov/complete\\_table.html](http://mecc.cancer.gov/complete_table.html)

Population and age structure vary considerably across the region, but the trend is towards increasingly young populations (Figure 3.3). This trend is particularly marked in Jordan (34% of the population < 14 years; 4% > 65+), the Palestinian Authority (45% of the population < 14 years; 3% > 65+), and Egypt (33% of the population < 14 years; 4% > 65+). It is less so in Turkey (26% of the population < 14 years; 7% > 65+) and Israel (26% of the population < 14 years; 10% > 65+) (12). In contrast to other MECC members, Cyprus has a slightly aging population (20% of the population < 14 years), with the greatest number of older people (12% are > 65+) and the longest life expectancy. Several socioeconomic factors contribute to this trend in Cyprus; for instance, there is a relatively large economically advantaged, retired population, including a significant number of non-Cypriots. Young people often have to seek educational and work opportunities off the island. These population patterns are relevant to the development and provision of effective palliative care. For example, aging populations tend to make high demands on health care services, particularly end-of-life care. In Cyprus, these needs have been addressed by some determined and dedicated individuals in the Greek Cypriot south. Their task is helped by the fact that the island is small and most areas accessible enough to enable teams to travel relatively easily, which has facilitated the development of effective home care services.

In contrast, the vast landscapes of Turkey, Egypt, and Jordan (the latter with much inhospitable desert terrain), tend to force the focus for all health care services into

large urban centers. This can leave small, widely dispersed rural populations seriously under-resourced. Where palliative care is undeveloped even in urban centers, the situation is particularly difficult for those in far-flung regions. In the case of the Palestinians, sheer pressure of population puts a massive strain on health care services, already in crisis as a result of the long-running political conflict. Although the land area is small, people have great difficulty traveling to treatment centers, as the conflict restricts free access across the region.

## HUMAN DEVELOPMENT IN THE REGION

The human development indicators (HDI) (13) longevity, knowledge, and standard of living, when measured in the MECC region, show marked variations in levels of development within the individual countries (Table 3.2).

Israel and Cyprus are located in the high range of development and share similar levels of high life expectancy (Israel, 79 years; Cyprus, 78 years), high levels of education, and percentage of adult literacy within the population (Israel, 79%; Cyprus, 78%), as well as a relatively high standard of living (Gross Domestic Product [GDP] Index (14): Israel, 0.88; Cyprus, 0.87). Jordan and Turkey are ranked closely in the HDI medium range of development. Both countries share similar levels of relatively lower life expectancy (Turkey, 70 years; Jordan, 71 years). Jordan has a higher level of education and percentage of adult literacy within its population (Jordan, 91%; Turkey, 87%) but a slightly lower standard of living than Turkey (GDP Index: Jordan, 0.67; Turkey 0.69). The Palestinian Authority and Egypt are ranked lower in the medium range. Although the Palestinian Authority is on a par with Jordan and Turkey, sharing similar life expectancy (72 years) and slightly higher levels of education and percentage of adult literacy within its population (Palestinian Authority, 90%), it has considerably more poverty per capita and a lower standard of living than either Jordan or Turkey (GDP Index: Palestinian Authority 0.52). Egypt has the lowest HDI ranking of all the MECC members, with the lowest life expectancy at 69 years, low levels of education, and only 56% literacy within its population. Nevertheless, Egypt has a higher standard of living (GDP Index: 0.61) than the Palestinian Authority.

## HEALTH CARE SYSTEMS COMPARED ACROSS THE MECC MEMBER REGION

Health care systems across the region are, without exception, based upon government-funded services; however,

**Table 3.2. Human Development Index (HDI) in MECC member region, 2006**

	HDI value	Rank/177	Level of development
Cyprus	0.903	29	High
Egypt	0.702	111	Medium
Israel	0.927	23	High
Jordan	0.760	86	Medium
Palestinian Authority	0.736	100	Medium
Turkey	0.757	92	Medium

Source: UNDP (HDI) Report 2006 – data <http://hdr.undp.org/hdr2006/statistics/indicators/1.html> (accessed 15 Jan 2007)

Table 3.3. Summary of main providers of health care services across the MECC region

	Primary Care		Hospitals/ Nursing Homes		Community Services		Private	NGO*
	Government Ministry of Health (MoH)	Health Insurance --public/ not- for-profit (HI)	MoH	HI	MoH	HI	Including HI schemes, i.e. for primary care, hospitals, nursing homes	
Cyprus			X		Developing		X	X
Egypt			X		X		X	
Israel	X	X	X	X	X	X	X	X
Jordan			X	X	X	X	X	
Palestinian Authority	X	X	X	X	X	X	X	X
Turkey			X	X	X	X	X	X

\*Non-government organization

there is considerable variation between systems, in terms of the proportion of government-funded services versus health insurance-funded services that are either not-for-profit or privately run (Table 3.3).

Each MECC member has developed a range of funding routes and service provision. The absence of primary care systems is notable in some parts of the regions, although some MECC members provide community health services for mothers and children or nursing services for older people. All countries maintain a government public health service that is responsible for monitoring community

**Table 3.4. WHO overall health system performance (efficiency) score (where 1 is the most efficient and 191 the least efficient), 2001**

	Rank/191 countries <sup>a</sup>
Cyprus	24
Egypt	70
Israel	28
Jordan	83
Turkey	88

<sup>a</sup> There are no WHO data for the Palestinian Authority.  
Source: Tandon A, Murray C.L.J, Lauer J.A, Evans D.B. Measuring overall health system performance for 191 Countries, GPE Discussion Paper Series: No 30; WHO [www.who.int/health-systems-performance/docs/efficattain\\_docs.htm](http://www.who.int/health-systems-performance/docs/efficattain_docs.htm)

health, including control of epidemics and provision of maternity and child health services, vaccination programs, and psychiatric services. Many public health departments oversee preventative health initiatives such as campaigns to promote anti-smoking, cancer prevention, or the control of tuberculosis or HIV/AIDS.

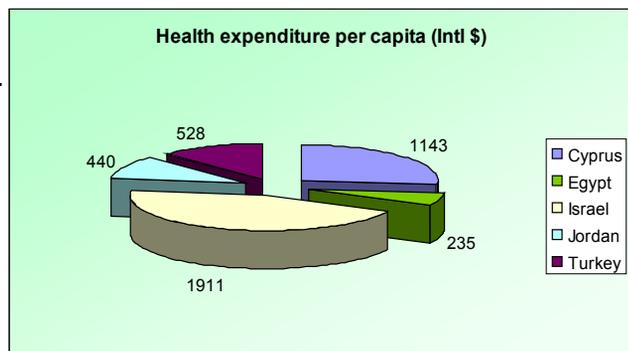
The efficiency of overall health system performance--as measured by the World Health Organization (WHO)--is highest in Israel and Cyprus (Table 3.4) (15).

Although Egypt has a higher-ranking health system performance than Jordan or Turkey, it actually has the lowest levels of per capita health expenditure in the MECC region. This apparent anomaly may arise because Jordan and Turkey preside over significant health inequalities, and within the context of poorer economies, greater inequalities of wealth.

In the MECC region, as Figure 3.4 illustrates, health care expenditure, measured in International US dollars (Intl \$), is highest per capita in Israel (Intl \$1,911) and Cyprus (Intl \$1,143). Turkey (Intl \$528) and Jordan (Intl \$440) have considerably lower expenditure. Egypt (Intl \$235) has the lowest expenditure per capita. No data are available for the Palestinian Authority for per capita expenditure on health care.

Expenditure ranking is reflected in the data giving health care as a percentage of GDP, as illustrated in Figure 3.5.

**Figure 3.4. Total health expenditure (Intl \$) per capita in the MECC region,\* 2003**



\*No data available for Palestinian Authority.

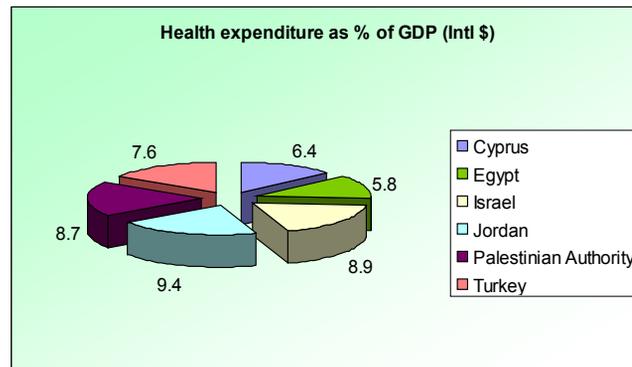
Source: World Health Organization (WHO) Report 2006  
<http://www.who.int/countries/en/>

In 2003, MECC members spending the highest percentage of GDP on health care were Jordan (9.4%), Israel (8.9%), and Turkey (7.6%). Cyprus (6.4%) and Egypt (5.8%) were in the lowest range of spending. The Palestinian Authority spends a relatively high percentage of GDP (8.7%) on health care, despite serious economic problems. To some extent, this may reflect a situation where a significant part of a relatively low level of governmental expenditure is taken up by the high demand for health care services.

Individual MECC members' health care systems often involve complex arrangements between government ministry of health (MoH) departments and health insurance schemes that are run variously by government, by government-approved not-for-profit independent insurers, or by private insurers. All MECC members have private-sector health providers offering a range of hospital and individual consultation services, though very rarely including palliative care.

Cyprus has no primary care or community medicine services, although at the time of writing a community-nursing scheme is being developed in the capital, Nicosia. Health care services are provided to all Cypriot residents via government-funded hospitals in the Greek Cypriot south of the island. Medical cards entitling eligible residents to free or reduced-payment services are issued from the MoH. Residents not eligible for a medical card pay for all treatments according to a sliding scale of charges. Private-sector primary and hospital health care is available throughout the south. Turkish Cypriot patients with cancer can access free services provided by the two not-for-profit NGOs in the Greek Cypriot south; Turkish Cypriots in the

**Figure 3.5. Total health expenditure as a percentage of GDP in the MECC region, 2003**



Source: World Health Organization (WHO) Report 2006  
<http://www.who.int/countries/en/>

north have access to government health provision as on the Turkish mainland, and this does not currently include palliative care services.

In Egypt, the government provides a health insurance scheme for all eligible residents, and there are government-funded hospitals and community clinics throughout the country.

Israel has a health care system based on health plans provided by four not-for-profit institutions. Originally known as "sick funds," and established in 1948 by workers' associations, they were politicized by affiliation with different party factions. Before 1995, when the government National Health Insurance (NHI) law was introduced, Israelis paid voluntary contributions into the health plan of their choice. Since 1995, contributions to the health plan of choice have been collected compulsorily as health tax; in exchange, all Israeli citizens, irrespective of their income or age, are entitled to full medical insurance with a health benefits package (stipulated by the NHI) from the health plans. Individuals can also pay additional Voluntary Health Insurance (VHI) for supplements to their basic benefits, which cover private medical provision and complementary therapies. There are four health plans, known as Health Maintenance Organizations (HMOs): Clalit (the largest and oldest HMO, still insuring around 55% of the public), Maccabi (24%), Meuhedet (11%), and Leumit (10%). The government role, carried out by the MoH, is to provide services not covered by HMOs; most importantly, this covers public health, including communicable disease control, mother and baby care, psychiatric care, and long-term hospitalization. The MoH also subsidizes

some HMO activities by an NHI per capita reimbursement system, and also plans, supervises, regulates, and licenses different aspects of health services. The MoH has developed, owns, and operates government-funded hospitals, which account for around half all the acute beds in Israel (16). Currently, palliative care services are not a stipulated NHI benefit or an essential component of the health plans' "basket of services." Health funding for palliative care is discretionary from the HMOs and the degree to which they are prepared to fund services either completely or, depending on whether the service is based within a health plan institution, in part alongside MoH funds or charitable monies.

The Jordanian health system operates through health insurance schemes, with 59% provided through private health insurance (17). Government health insurance schemes are available for government employees (civilian and military) and their families. Royal Court insurance provides funds for 90% of the costs for all cancer patients (18). Health services are delivered through governmental and private hospitals, family/community health centers, and hospital-based health professionals. Since the early 2000s, the MoH has been developing a primary health care system through family health centers (19).

The Palestinian Authority provides a health insurance scheme for government employees and funds government hospitals. In 2003, an estimated 28% of the population was enrolled in health insurance plans (20). The majority of the population, however, relies heavily on charitable, United Nations, and other foreign aid programs, such as the United Nations Refugee and Works Administration (UNRWA) and the Union of Health Work Committees (UHCW), among others, to support access to health care and provide services. Access to medical care is severely hindered by the difficulties of traveling within the territories and getting through checkpoints. Hence, small clinics have been built to provide some basic health care in areas without easy access to the major hospitals. Volunteers are also trained to provide basic health care support in refugee camps and isolated communities (21). Of 619 primary health care centers in the Palestinian Authority, around 63% are government funded; the remainder are NGO funded (22).

Of all MECC members, Turkey has the most complex health care system: a partly nationalized health care service established in 1961, and a well-established private sector. As Savas et al. explain: "Turkey's health care system is at once centralized and fragmented. Health care is provided by public, quasi-public, private and philanthropic organizations but relations among them are not well structured or regulated. Health care is financed by the government

(through the Ministry of Finance), social security institutions such as the Social Insurance Organization (SSK), the Social Insurance Agency of Merchants, Artisans and the Self-employed (Bag Kur), and the Government Employees' Retirement Fund (GERF) and private, out-of-pocket, payments." (23)

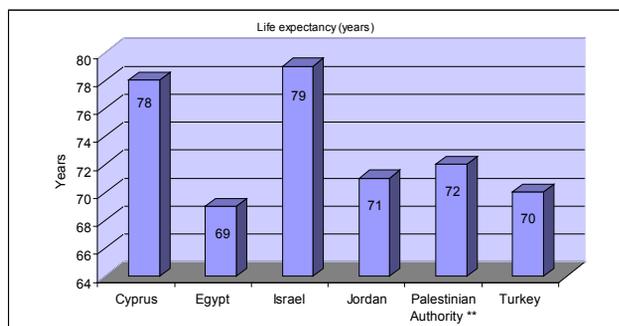
The government public health services in Turkey include MoH hospitals, health clinics, specific health centers (family, maternal and child health, tuberculosis dispensaries), Ministry of Defense military hospitals, and Higher Education Council-funded university hospitals (24). Philanthropic organizations include the Red Crescent, which provides aid in natural and war-related disasters, as well as support in dispensaries. A variety of philanthropic NGOs, known collectively as the "Foundations," offer help to people with illnesses such as diabetes, cancer, and AIDS, but as yet, not for palliative care. People can access free services (including inpatient medication, but excluding outpatient prescriptions) in all MoH institutions and when referred to university hospitals if they have a "low income" Green Card. The municipalities of the three largest cities run their own hospitals and offer free home care for the poor, which includes care at the end of life (25). People without a Green Card cover their medical costs either through one of the three social security government schemes (SSK, Bag-Kur, GERF), or they have private health insurance. Estimates by the State Planning Organization suggest that roughly 83% of the population have state health coverage. In total around 87% of the population are covered by some kind of state or private insurance, either directly or as a dependent. The actual figures are thought to be lower. Over half the population of more than 73 million contribute to one of the social security schemes, and 34 million contribute to the SSK, the most flexible and comprehensive scheme. There are continuing concerns that a substantial proportion of the population is not covered by insurance, or that some schemes offer inadequate coverage. This is especially problematic for people at the end of life; some government insurance schemes do not cover outpatient prescribed medication, which means many people have to be hospitalized if they or their families cannot afford the costs of medication when at home. Conversely, private health care at the end of life is not always available. Many private nursing homes will not admit patients who are known to be in the terminal stage of their illness (26).

## EPIDEMIOLOGY AND PUBLIC HEALTH

Epidemiological and public health issues are essential indicators of the dimension of end-of-life care needs in different countries and areas (1).

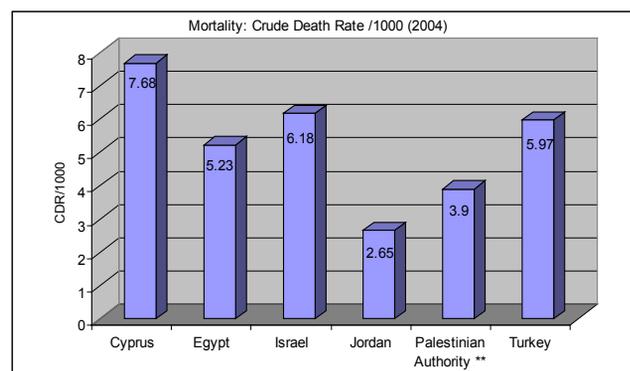
Figures 3.6 and 3.7. Comparison between life expectancy at birth (years) and mortality rates (crude death rate (CDR)/1000 population) in MECC populations, 2004

Figure 3.6. Life expectancy at birth (years)



Source: WHO statistics (2004 est.): <http://www.who.int/countries/en/>

Figure 3.7 Mortality rates



Source: World Factbook <https://www.cia.gov/cia/publications/factbook/index.html>

There are distinct and variable patterns of life expectancy at birth and rates of mortality (crude death rate) (27) in populations across the MECC region (see Figures 3.6 and 3.7). Cyprus and Israel, with older populations but better standards of living, have longer life expectancy but a higher mortality rate in quite sharp comparison to the other MECC members. Mortality rates in Turkey and Egypt are on a par with Cyprus and Israel, but coupled with lower life expectancy may reflect poorer standards of living with concomitant higher rates of life-limiting diseases at younger ages. In comparison, the lower mortality rates in the Palestinian Authority and Jordan together with lower life expectancy may reflect a younger population combined with poor standards of living.

The prevalence of specific diseases is similar throughout the region, although where figures are available, incidence and rates of death from specific diseases vary within the different populations. Consistent across the whole region is the prevalence of cardiovascular and heart disease,

Table 3.6. Primary causes of death in MECC region, 2004

	% primary causes of death			
	Cardio/heart	Cancer	Injuries	AIDS
Cyprus	60	13	4.0	0.00
Egypt	42	8	2.0	0.10
Israel	31	27	5.6	0.00
Jordan	31	14	16.0	0.00
Palestinian Authority	25	10	11.0 <sup>a</sup>	0.00
Turkey	54	11	6.4 <sup>a</sup>	0.02

<sup>a</sup> indicates deaths included from injuries resulting from war and conflict

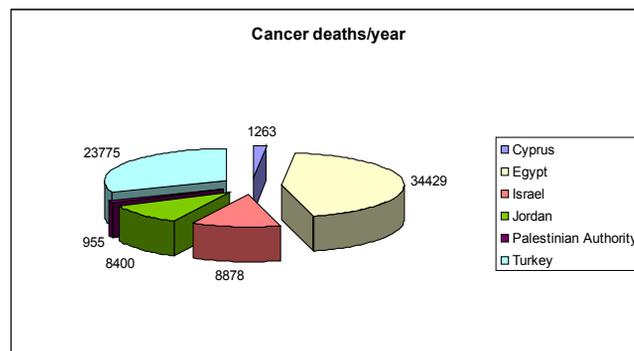
Source: percentages calculated using WHO December 2004 statistics: estimates of total deaths (2002) <http://www.who.int/healthinfo/statistics/bodgbddeathdalyestimates.xls>

\*Statistics from Palestinian Authority from WHO Health Crisis in Action Report, July 2006 [http://millenniumindicators.un.org/unsd/mi/mi\\_results.asp?crID=275&fID=15](http://millenniumindicators.un.org/unsd/mi/mi_results.asp?crID=275&fID=15)

accounting for over a quarter to half of all deaths (Table 3.6).

Cancer is the second most common cause of disease-related death throughout the region. In Jordan, road accidents

Figure 3.8. Comparative total cancer deaths /annum, 1998-2003



Source: Cyprus: cited from Cancer Research UK, Information Resource Centre, Cancer in the EU: incidence and mortality in the European Union based on estimates in 2000. [info.cancerresearchuk.org/cancerstats/cancerineu/incidenceandmortality/](http://info.cancerresearchuk.org/cancerstats/cancerineu/incidenceandmortality/). Accessed 29th June 2005

Egypt and Jordan: Ferlay J, Bray F, Pisani, P, Parkin DM. (2001) GLOBOCAN 2000: Cancer incidence, mortality and prevalence worldwide. V1.0 IARC Cancerbase No.5 Lyon: IARC Press, 2001

Israel: Calculated from returns by Israel Ministry of Health Statistics 2002 [www.health.gov.il/english/](http://www.health.gov.il/english/)

Palestinian Authority: Salhab, A.R. and El Najjar, K. (2001) Palestinian National Cancer Registry: Cancer Incidence in Palestine, 1998-1999, Palestinian National Authority, Ministry of Health

Turkey: State Institute of Statistics (T.C. Basbakanlik, Devlet Istatistik Enstitusu) (2004), Turkey's Statistical Yearbook 2004, State Institute of Statistics, Prime Ministry, Republic of Turkey [www.die.gov.tr/yillik/yillik\\_2004\\_eng.pdf](http://www.die.gov.tr/yillik/yillik_2004_eng.pdf)

are the second most common cause of death (16%). In the Palestinian Authority, WHO reports that in 2004 the primary cause of death “for the age groups 1-4 (22.9%), 5-19 (56.1%), and 20-59 (29.3%)” was “injuries, whether domestic, road or conflict-related” (estimated as 11% of deaths in the whole population) (28).

The numbers of cancer-related deaths correlate with the relative population size in Egypt and Turkey (both large populations with the highest number of cancer-related deaths per year), and in Israel and Jordan (of similar population size, and reporting comparable numbers of cancer deaths). Israel has the highest percentage/population of cancer deaths of all MECC members in the region. Freedman et al. note, for instance, the incidence of lymphoma in Israeli Jews is one of the highest in the world (1). Cyprus has a disproportionately larger number of cancer deaths than the Palestinian Authority, but this is likely to be influenced by the older average age of the Cypriot population relative to the younger average age of the Palestinian population (Figure 3.8) (29).

Throughout the MECC region, lung cancer is the most common cancer in men; breast cancer is the commonest cancer in women (1). For example, in 2003 the reported incidence in Egypt of breast cancer in women represented 18.9% of the country’s total cancer cases. In Israel, of 21,000 new cases of cancer reported in 2002, lung cancer in men accounted for 4.5% of all new cancer cases and 9.7% of all cancer deaths; breast cancer in women accounted for 15% of all new cases and 10.3% of all cancer deaths (30,31). The Palestinian Authority had 1,730 new cancer cases in 1999 (32).

In Turkey in 2003, cancer accounted for 13% of all registered deaths (8% of deaths in men; 5% of deaths in women) (34,35). Cancers of the trachea, bronchus, and lungs were the most common in men (61.6% annual incidence). Breast cancer was the most common in women (24.4% annual incidence) (36). Colorectal cancer was the second most common cancer. The prevalence of lung, breast, and colorectal cancer is similar to cancer incidence percentages across Europe (37).

UNAIDS (2004) (38) reports the incidence of HIV/AIDS as very low in Jordan and the Palestinian Authority (prevalence <0.1%). There is no systematic HIV surveillance in Jordan, and available data consist mainly of compiled testing results among blood donors and foreign workers residing in Jordan (39). HIV seroprevalence among blood donors still remains below 0.03% in Jordan. There are no UNAIDS reports for Turkey, but in 2004 the Turkish State Statistics Institute reported that a total of 197 HIV/AIDS cases had been reported by the end of 2003

(40). In Turkey, tuberculosis is a greater problem than HIV/AIDS, with an estimated 18,000 people undergoing treatment each year (40). Numbers of HIV/AIDS cases are slightly higher in Cyprus, Egypt, and Israel. UNAIDS notes that in Cyprus, “Since the start of the epidemic [data registered from 1986] and as of May 2003, 400 persons have been diagnosed with HIV, but no AIDS deaths have been reported.” (41) Egypt has a very low prevalence of HIV/AIDS (<0.2%) compared with other African countries, but relatively high prevalence compared with other populations in the MECC region. Estimates suggest that between 5,000 and 31,000 people were living with HIV/AIDS in Egypt at the end of 2003. In the same year, up to 1,600 adults and children are thought to have died from the disease.

In comparison to Egypt, Israel has low rates of HIV/AIDS. UNAIDS (2004) suggests that around 5,000 people with HIV/AIDS were living in Israel (prevalence 0.1%—0.2%) (42). An epidemiological study on the change in rates and pattern of infection in Israel from 1991 to 2000 reports a rise in HIV incidence, thought to be mainly influenced by immigration of people from countries with a high incidence of the disease (43,44).

## CONCLUSION

MECC members Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey have widely different population patterns and human development indices. Their health care and public health systems reflect this demographic and economic diversity, despite many similarities in epidemiology across the region.

Cyprus and Israel, with relatively small populations in comparison to other MECC members, have the highest standard of living, and also have comparatively well-resourced and comprehensive health care services. Jordan, with a fairly small but rapidly growing young population, has a lower standard of living than Cyprus and Israel, but has a relatively well-resourced and developing health care system. Egypt and Turkey have the largest populations but with a standard of living similar to Jordan. Both countries have relatively comprehensive, though less well-resourced health care systems; they have significant inequalities in wealth and access to health care. The Palestinian Authority, located across two separate areas, both small but densely populated and with a rapidly expanding young population, struggles to provide adequate health care in the face of ongoing political conflict, limited access and scarce financial resources.

Across the MECC region, cardiovascular and heart disease accounts for over a quarter to half of all deaths. Cancer is

the second most common cause of disease-related death throughout the region. Israel has the highest percentage per population of cancer deaths. Due to the older average age of its population, Cyprus has a disproportionately higher number of cancer deaths than the Palestinian Authority, with a larger young population. There is a reportedly very low incidence of HIV/AIDS in the MECC region, with the highest number of cases of HIV/AIDS reported in Egypt.

The following chapters (4-9) provide detailed reports of current services and the history of palliative care development in Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey.

## ENDNOTES

1. Freedman LS, Edwards BK, Ries LAG, Young JL (eds.) Cancer incidence in four member countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) compared with US SEER. National Cancer Institute. NIH Pub. No. 06-5873. Bethesda, MD, 2006. This publication is available on the SEER web site at [seer.cancer.gov](http://seer.cancer.gov) under Publications, and on the MECC web site at [mecc.cancer.gov](http://mecc.cancer.gov) under Cancer Registry Project.
2. Egypt's population is made up of the following ethnic groups: Eastern Hamitic stock (Egyptians, Bedouins, and Berbers), 99%; Greek, Nubian, Armenian, other European (primarily Italian and French), 1%. Religious groups include: Muslim (mostly Sunni), 94%; Coptic Christian and other, 6%. Statistics from 2001: [www.cia.gov/cia/publications/factbook/geos/eg.html](http://www.cia.gov/cia/publications/factbook/geos/eg.html).
3. For more details, see the United Nations website [www.uneca.org/aisi/nici/country\\_profiles/Egypt/egyptab.htm](http://www.uneca.org/aisi/nici/country_profiles/Egypt/egyptab.htm).
4. Savas BS, Karahan O, Saka RO. In Thomson S & Mossialos E, eds. Health care systems in transition: Turkey. Copenhagen: European Observatory on Health Care Systems, 2002;4:4.
5. Turkey's population is made up of ethnic groups, the largest of which is Kurdish. Religious groups include: Muslim, 99.8% (mostly Sunni); other, 0.2% (mostly Christians and Jews).
6. The population of Cyprus is made up of the following ethnic groups: Greek, 77%; Turkish, 18%; and other, 5%. Religious groups include: Greek Orthodox, 78%; Muslim, 18%; Maronite, Armenian Apostolic, and other, 4%. (Statistics from 2001: [www.cia.gov/cia/publications/factbook/geos/cy.html](http://www.cia.gov/cia/publications/factbook/geos/cy.html).)
7. Al Kayed S & Al Hijawi B. (2005) Report of the National Cancer Registry, incidence of cancer in Jordan 2002, The Hashemite Kingdom of Jordan, Ministry of Health.
8. Jordan's population of around 5,329,000 is made up of the following ethnic groups: Arab 98%, Circassian 1%, Armenian 1%. Religious groups include: Sunni Muslim 92%, Christian 6% (majority Greek Orthodox, but some Greek and Roman Catholics, Syrian Orthodox, Coptic Orthodox, Armenian Orthodox, and Protestant denominations), other 2% (several small Shi'a Muslim and Druze populations) (2001 est.). [www.cia.gov/cia/publications/factbook/geos/jo.html](http://www.cia.gov/cia/publications/factbook/geos/jo.html).
9. The population of Israel is made up of the following ethnic groups: Jewish 80.1% (Europe/America-born 32.1%, Israel-born 20.8%, Africa-born 14.6%, Asia-born 12.6%), non-Jewish 19.9% (mostly Arab) (1996 est.). Religious groups include: Jewish 80.1%, Muslim 14.6% (mostly Sunni Muslim), Christian 2.1%, other 3.2% (1996 est.) [www.cia.gov/cia/publications/factbook/geos/is.html](http://www.cia.gov/cia/publications/factbook/geos/is.html).
10. For more details and a full country profile, see the United Nations website at [www.unodc.org/egypt/en/country\\_profile\\_israel.html](http://www.unodc.org/egypt/en/country_profile_israel.html).
11. The Palestinian Authority population is made up of the following ethnic groups: Palestinian Arab and other, 99.4%; Jewish, 0.6%. The West Bank population is made up of the following ethnic groups: Palestinian Arab and other, 83%; Jewish, 17%. Religious groups in the Gaza Strip include: Muslim (predominantly Sunni), 98.7%; Christian, 0.7%; Jewish, 0.6%. In the West Bank religious groups include: Muslim, 75% (predominantly Sunni); Jewish, 17%; Christian and other, 8%. [www.cia.gov/cia/publications/factbook/geos/we.html](http://www.cia.gov/cia/publications/factbook/geos/we.html).
12. Statistics from 2001: [www.cia.gov/cia/publications/factbook/geos/cy.html](http://www.cia.gov/cia/publications/factbook/geos/cy.html).
13. See Report of the United Nations Development Programme 2004 (Human Development Index 2002). Launched by the United Nations in 1990, the Human Development Index (HDI) measures a country's achievements in three aspects of human development: longevity, knowledge, and a decent standard of living. It was created to re-emphasize that people and their lives should be the ultimate criteria for assessing the development of a country, not economic growth. Current values range from 0.956 (Norway, 1/177 countries) to 0.273 (Sierra Leone, 177/177 countries). Countries fall into one of three groups: countries 1-55=high development; 56-141=medium development; 142-177=low development. See: [hdr.undp.org/statistics/data/indic](http://hdr.undp.org/statistics/data/indic).
14. GDP Index is an aggregate figure based on all relevant HDI data. For details of calculations of UNDP refer to: Statistical feature 2: Note to table 1: About this year's Human Development Index. [hdr.undp.org/statistics/data/indic](http://hdr.undp.org/statistics/data/indic).

15. This composite measure of overall health system attainment is based on a country's goals relating to health, responsiveness, and fairness in financing. The measure varies widely across countries and is highly correlated with general levels of human development as captured in the human development index. For details on how this measure is calculated, see Tandon A, Murray CLJ, Lauer JA, Evans DB. Measuring overall health system performance for 191 Countries, GPE Discussion Paper Series: No 30; WHO [www3.who.int/whosis/discussion\\_papers/pdf/paper30.pdf](http://www3.who.int/whosis/discussion_papers/pdf/paper30.pdf).
16. For full details of the health care history and structure in Israel, see Rosen B. In Thomson S & Mossialos E, eds. Health care systems in transition: Israel, Copenhagen: European Observatory on Health Care Systems 2003;5:1.
17. Banks DA, Millburn L, Sabri H. Profile of the uninsured in Jordan, Technical Report No. 37, PHR, 1999.
18. IOELC interview: Ahmad Al Khateib, 11 May 2005.
19. IOELC interview: Bassam Hijawi, 11 May 2005.
20. Health Indicators—health services. [www.moh.gov.ps/index.asp](http://www.moh.gov.ps/index.asp).
21. UNDP (2004) UNDP Focus, 3, published by United Nations Development Programme and the Programme of Assistance to the Palestinian People.
22. Health Indicators—health services. [www.moh.gov.ps/index.asp](http://www.moh.gov.ps/index.asp).
23. Savas B, Karahan O, Saka R. In Thomson S & Mossialos E, eds. Health care systems in transition: Turkey. Copenhagen: European Observatory on Health Care Systems, 2002;4:4.
24. Ministry of Health, Ankara, 2001. [www.saglik.gov.tr](http://www.saglik.gov.tr).
25. Email communication: Professor Yasemin Oguz—18 September 2005.
26. Oguz NY, Miles SH, Buken N, Civaner M. End of life care in Turkey, Cambridge Quarterly of Healthcare Ethics, 2003;12:279-284.
27. We have used the crude death rate (CDR/1000) because it is the only comparative measure where figures are available for all MECC members.
28. Source: Cited from Cancer Research UK, Information Resource Centre “Cancer in the EU: incidence and mortality in the European Union” based on estimates in 2000. Accessed 29th June 2005 [info.cancerresearchuk.org/cancerstats/](http://info.cancerresearchuk.org/cancerstats/).
29. Ferlay J, Bray F, Pisani P, Parkin DM. GLOBOCAN 2000: Cancer incidence, mortality and prevalence worldwide, v1.0 IARC Cancerbase No. 5 (Lyon: IARC Press), 2001.
30. All figures in this section have been calculated from returns by the Israel Ministry of Health Statistics 2002 [www.health.gov.il/english/](http://www.health.gov.il/english/).
31. Omar S, Khaled H, Gaafar R, Zekry AR, Eissa S, El-Khatib O. Breast cancer in Egypt: a review of disease presentation and detection strategies, La Revue de Santé de la Méditerranée orientale, 9, No. 3, 2003. [www.emro.who.int/Publications/EMHJ/0903/PDF/26%20Breast%20Cancer%20in%20Egypt.pdf](http://www.emro.who.int/Publications/EMHJ/0903/PDF/26%20Breast%20Cancer%20in%20Egypt.pdf).
32. The Palestinian Authority developed the Cancer Registration Project in 1998, with the support of MECC, the National Cancer Institute, Bethesda, MD, and the International Agency for Research on Cancer (IARC).
33. Salhab, AR and El Najjar K. Palestinian National Cancer Registry: Cancer Incidence in Palestine, 1998-1999, Palestinian National Authority, Ministry of Health, 2001.
34. State Institute of Statistics (T.C. Basbakanlik, Devlet Istatistik Enstitusu) (2004) Turkey's statistical yearbook 2004, State Institute of Statistics, Prime Ministry, Republic of Turkey. [www.die.gov.tr/yillik/yillik\\_2004\\_eng.pdf](http://www.die.gov.tr/yillik/yillik_2004_eng.pdf). Actual figures: 23,775 male and female total deaths from neoplasm; 184,330 male and female total all deaths.
35. “The Izmir Cancer Registry (ICR) is a recording and research center that collects cancer data from the whole population in line with international standards, since April 1992. Not only all of the hospitals of Izmir province concerned with cancer diagnosis and/or therapy, but also all oncology centers and pathology laboratories are among the data resources of ICR. Software of ICR is CanReg-4 of IARC (International Agency for Research on Cancer) and the coding base is the Turkish version of ICD-O-3. ICR is a member of IARC (International Association of Cancer Registries) and ENCR (European Network of Cancer Registries).” The first international paper of the center was published in 2001: Fidaner C, Eser SY, Parkin DM. Incidence in Izmir in 1993–1994: first results from Izmir Cancer Registry, European Journal of Cancer, 2001;37,83-92. [mecc.cancer.gov/turkey.html](http://mecc.cancer.gov/turkey.html).
36. Izmir Cancer Registry [www.ato.org.tr/konuk/kidem/Edoc3.htm](http://www.ato.org.tr/konuk/kidem/Edoc3.htm).
37. Boyle P and Ferlay J. Cancer incidence and mortality in Europe, 2004 Annals of Oncology 2005;16:481-488.
38. Source cited from UNAIDS 2004 Update: Cyprus at: [data.unaids.org/Publications/Fact-Sheets01/cyprus\\_en.pdf?preview=true](http://data.unaids.org/Publications/Fact-Sheets01/cyprus_en.pdf?preview=true).
39. El-Tayeb EM. Strengthening AIDS/HIV Surveillance in Jordan: 17-31 October 1994, World Health Organization, Regional Office for the Eastern Mediterranean, February, Assignment report, 1995.
40. State Institute of Statistics (T.C. Basbakanlik, Devlet Istatistik Enstitusu) (2004) Turkey's statistical yearbook 2004, State Institute of Statistics, Prime Ministry, Republic of Turkey [www.die.gov.tr/yillik/yillik\\_2004\\_eng.pdf](http://www.die.gov.tr/yillik/yillik_2004_eng.pdf).
41. Source: EMCDDA 2003 [candidates.emcdda.eu.int/en/page70-en.html](http://candidates.emcdda.eu.int/en/page70-en.html).
42. “In 2003 and during the first quarter of 2004, UNAIDS and WHO worked closely with national governments and research institutions to recalculate current estimates on people living with HIV/AIDS. These calculations are based on the previously published estimates for 1999 and 2001 and recent trends in HIV/AIDS surveillance in various populations.” [www.unaids.org](http://www.unaids.org).

43. Chemtob D and Grossman Z. Epidemiology of adult and adolescent HIV infection in Israel: a country of immigration, *International Journal of STD & AIDS*, 2004;15:691-696.
44. Since the mid-1990s, an Israeli NGO, The Jerusalem AIDS Project, has run regular training workshops for health professionals and “supports an ongoing network of concerned health professionals, devoted to AIDS prevention.” For details, see Schenker I (1997) HIV/AIDS in the Middle East and Israel: The Jerusalem AIDS Project, *Shalom Magazine* 2 [www.jewishvirtuallibrary.org/jsource/Health/HIV.html](http://www.jewishvirtuallibrary.org/jsource/Health/HIV.html).



# Chapter 4

## Palliative Care in Cyprus

Cyprus (population 775,927) is an island republic covering an area of 9,250 square kilometers in the far northeastern corner of the Mediterranean Sea. The island of Cyprus has been divided since 1974, when conflicts between the Greek Cypriot majority and the Turkish Cypriot minority culminated in a Turkish military invasion. The UN buffer zone, known as the “Green Line,” separates the two ethnic communities inhabiting the island (Greek Cypriots in the south and Turkish Cypriots in the north). This separation dominates Cypriot life and has a significant impact on provision of health services in the two communities. The internationally recognized Greek Cypriot Republic of Cyprus in the south is now a member of the European Union, having joined in May 2004 (see Appendix 3) (1).

### PALLIATIVE CARE SERVICE PROVISION

#### Current services

There are two nongovernmental organizations (NGOs) providing palliative care services in the Greek Cypriot

south: The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF), and the Cyprus Anti-Cancer Society (CACS).

Supportive care is also provided in three hospital oncology units; two are government-funded, and one is joint government- and commercially-funded. A total of eight palliative or supportive care services are provided across the Greek Cypriot south (Table 4.1). There are no palliative care services for Turkish Cypriots in the north, but there is some voluntary support for cancer patients. Palliative care services in Cyprus currently only provide for adult patients with cancer.

The Cyprus Anti-Cancer Society runs three services:

- 18-bed inpatient unit at the Arodaphnousa Hospice in Nicosia;

- home care service based at the hospice that covers all districts in the Greek Cypriot south;

**Table 4.1 Palliative care provision in Cyprus, 2005**

Adult Services							
	Freestanding unit	Hospital unit	Hospital support team	Home care	Day care	Clinic/ Drop-in center	Grand Total
The Cyprus Association of Cancer Patients and Friends				1	1		2
Cyprus Anti-Cancer Society	1			1	1		3
<b>Government-funded oncology units:</b>							
~Nicosia General Hospital Oncology Center		1					
~Limassol Hospital Oncology Unit		1					
<b>Commercially-funded unit</b>							
~ Bank of Cyprus Oncology Center		1					3
<b>Total</b>	<b>1</b>	<b>3</b>		<b>2</b>	<b>2</b>		<b>8</b>

**Table 4.2 Patient attendances in the different services run by the Cyprus Anti-Cancer Society – activity from 1999-2004**

Service	Attendances per year	
	1999	2004
Arodaphnousa Hospice (inpatient)	145	276
Hospice home care (daytime only)	280	660
Day care (twice weekly)	-	14-18 per center
<b>Total attendances – all services</b>		<b>1400</b>

day care centers open twice a week in four districts: Nicosia, Limassol, Paphos and Famagusta (see Table 4.2).

Patients, or their families, can self-refer to the Society. Gradually since the mid-1990s, as links have improved with the oncology centers, more patients are referred by oncologists.

The Arodaphnousa Hospice has increased the number of patients treated each year in the inpatient unit by reducing unnecessary and lengthy inpatient stays. Once symptoms are controlled patients are able to return home, only returning for inpatient treatment if needed. With improvements to the home care service the numbers of patients treated at home increased from 280 in 1999 to 660 in 2004 (2). A total of 1400 patients in 2004 attended one or more home care, inpatient, or day care services, all of which provide medical and nursing care, psychosocial support, and physiotherapy (3). The four day care centers also offer a range of other services which can include music and art therapy, aromatherapy, reflexology, massage, hairdressing and manicure. Free transportation is provided for patients to access services, which in 2004 transported around 400 patients (4).

The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF) offers three services, including home care, day care and psychosocial support (see Table 4.3).

Within these services the Association runs a lymphoedema clinic and a psychosocial support team. Additional services offered include:

social support and activities;

a free prosthesis service;

a stop smoking clinic;

free transport to oncology units and day care centers;

financial help in situations where patients and their families are suffering hardship as a result of the illness.

### *Hospital oncology and specialist units*

There are now two oncology units in government-funded hospitals which offer supportive care and some palliation (5) at the end of life to cancer patients: Nicosia General Hospital Oncology Center (6) and the oncology ward in Limassol Hospital. There is also the joint government- and commercially-funded Bank of Cyprus Oncology Center, in Nicosia, which opened in 1998 (7,8). There is a six-bed specialist AIDS ward in Larnaca Hospital.

Cancer patients, and their families, may opt for the patient to stay in one of these oncology units, where they can now receive specialist pain and symptom relief, or they may decide to self-refer or be referred to one of the two organizations providing the full range of palliative care cancer services (3). There are no private palliative care services available.

There are no specialist palliative care services for children or for patients with other life threatening illnesses such as AIDS, but there is some interest in offering supportive care for these groups of patients, as Jane Kakas of The Cyprus Association of Cancer Patients and Friends describes:

“There is an AIDS department in Larnaca Hospital, but I don’t think they see themselves under the umbrella of

**Table 4.3 Patient numbers in the two key services run by the Cyprus Association of Cancer Patients and Friends – activity from 1998-2003**

Service	Attendances per year	
	1998	2003
Home Care Service (5 daytime teams)	700	791
Day Care (4 units, each opens twice weekly)	-	75
▪ psychosocial support service	1277	1204
▪ other supportive and clinical services	-	120
▪ transportation service	-	634

palliative care. We invite them [to seminars], and we send them anything interesting that comes through. If there was something that was relevant I would keep them informed, same as I do with the pediatric oncologist. I always send him copies of anything that comes through, especially related to opioids or pain in children. They do use morphine with children. But children don't really die at home, they tend to be admitted to the ward and given IV fluids with morphine. At least they are using morphine now for the children, which is a move forward. There are no government community services in Cyprus so families don't feel secure to have the children at home. They would love to have community services, of course, but it's a long way off." (9)

Since 2003, Turkish Cypriots can access the inpatient and day care hospice services in the Greek Cypriot south. Although no palliative care at home is available in the north, there are two NGOs that aim to offer support for cancer patients.

The Help Those with Cancer Association is run by volunteers (many are cancer survivors) and, with the help of a small number of nurses, it offers some limited home nursing care and support, as well as social and financial support to cancer patients during and following treatment, including those at the end of life. Volunteers will also support families, if needed, after a patient has died (10).

The Kemal Saracoglu Anticancer and Anti-leukemia Association aims to offer support for Turkish Cypriot patients, but as of June 2005, the Association remains at the planning stage in developing a home care service (11).

### **Reimbursement and funding for services (12)**

Cancer patients needing palliative care in the Greek Cypriot areas of the island are offered free services funded by either one of the two charitable organizations:

The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF) is given an annual government subsidy, which in 2004 was CY£90,000. From 2005, due to problems with government funds, the subsidy is being reduced to around CY£70,000. The Association raises the rest of the total CY£1 million it needs to run its services entirely from public donations (9).

The Cyprus Anti-Cancer Society is given an annual government subsidy, up to 2003 this was CY£10,000. From 2004 the government has reduced its subsidy to CY£1000. The remainder of the required annual budget of more than CY£1 million is raised mainly from public donation, with some additional commercial sponsorship (13). There is an annual, highly popular fund-raising event in Nicosia called the Christadoula March, dedicated to the memory of "Christadoula," a woman who died of

breast cancer during the 1974 hostilities, and her doctor Demitris Soultis, who inspired the formation of the Society to help cancer patients (14). In April each year marches are held in cities all around the south of the island, along with other fund-raising events, during which the majority of public donations are pledged (2).

The Cyprus government provides free medication via the oncology departments in local hospitals, and also for inpatients at the hospice. The hospice has access to laundry services via Nicosia General Hospital. There are no palliative services (in government-funded hospitals) for patients with other life-threatening illnesses. There are no private (fee-paying) palliative care services in Cyprus. Government health provision in all government-funded (including joint- and part-funded) hospitals or centers is free or at reduced payment for residents who are categorized as eligible for a medical card. Non-eligible residents are required to pay varying rates for different services (15).

### **Opioid availability and consumption**

Opioids and other related medications are available in all Greek Cypriot areas of Cyprus. Where necessary, opioids are given by injection and syringe drivers are used for pain relief in home care patients. However, there are still some problems accessing oral opioid preparations in larger dosages. As Sophia Pantekhi explains:

"We're trying to follow the guidelines from the pain step ladder of the World Health Organization (WHO). We have enough medication for pain control: MST, sevredol, oromorph, and fentanyl patches. We don't have any other kind of morphine like oxycodone or hydromorphone. If we want to improve pain control, we need higher dosages of sevredol tablets, at the moment we only have sevredol 10 and 20 mg. We need to increase awareness in health care professionals about how and when to prescribe opioids for their patients." (2)

The problem of ensuring that opioid medications are prescribed safely has required that teams trained in palliative care educate health professionals (physicians, pharmacists and nurses) throughout the health system, as well as giving clear instructions to the patient. Jane Kakas, a British clinical nurse specialist with palliative care training and experience, describes the shift in understanding that took place in 1997, following a conference on palliative care pain relief:

"After the Cancer Pain conference in '97 here in Limassol, we met many worldwide palliative care specialists and some people from the WHO, including David Joranson—we realized that we have to be not just a cancer association, we have to look at palliative care issues. One of the issues was that we didn't have enough basic

formulations of opioids in Cyprus. So we got together a presentation and we presented to oncologists, government doctors, pharmacists and any other doctors, anyone that was remotely connected, drug reps, anesthetists. We told them that although there are many options of new drugs on the market we believe you only need to have a small handful of drugs. So we suggested five formulations and an alternative opioid. Janssen was there already introducing Durogesic anyway. And we took this forward and with the backup of one specific oncologist and government pharmacists who understood what we were saying—we presented it to the government and they said yes and they ordered them for us. So we got of MST 10 mg and 100 mg, morphine in 30 ml ampoules of (we don't have diamorphine here), and we needed this morphine for the syringe drivers. We also got morphine suppositories and MST 30 mg in sachets for easy swallowing. We tried to influence doctors and nurses about how to use these new drugs, and even the pharmacists—I always mention the pharmacists because pharmacists play a huge role, and they have to know why somebody's going to the hospital to collect so many ampoules of morphine for the syringe driver. If they're not aware of what a syringe driver is and that's why we require a large dose of morphine regularly, they question the patient and sometimes send them away and tell them, 'Why do you need all this? You had some three days ago. You can't come back for more.' We just need to convince the policymakers that it's okay and the pharmacists should have adequate information and education. So the achievement, I think, was to get the medications imported and dispensed by the government pharmacies. For us in home care who knew how to use them it was great because we were suggesting to the doctors to please prescribe that and we were very happy as they were, mostly, willing to cooperate with us."

As Jane Kakas points out, there is still a great need to develop a protocol and to continue to provide basic education in palliative pain control:

"We need to have some protocols and education for the selection of patients that go onto fentanyl because

sometimes patients who are not stable on their pain control are prescribed fentanyl. Some doctors aren't sure of the basic WHO ladder, they're not aware of breakthrough pain, they're certainly not aware of breakthrough pain dosages when using Durogesic, so there's a huge amount of work to be done still on very basic symptom control. Now I know there are great opportunities for oxycodone and all these other things. But I think we are not ready to handle more opioids than we already have. There's a risk of confusing people, and the stuff we've got, they don't know how to use that yet. So there's a lot of basic education still needs to be done on that front." (9)

### Palliative care coverage

There are palliative care inpatient facilities at the Arodaphnousa Hospice in Nicosia. Pain and symptom relief is offered at the inpatient oncology unit within the general hospital in Nicosia—and at the Bank of Cyprus Oncology Centre. In Limassol there are facilities for care on the oncology ward in the general hospital. In Larnaca there are facilities for care of AIDS patients on the specialist ward in the general hospital (see Table 4.4).

The two palliative care NGOs provide home care teams throughout the five Greek Cypriot administrative districts (Larnaca, Limassol, Paphos and in Greek Cypriot areas of Nicosia and Famagusta). There are day care centers in all five Greek Cypriot districts offering patients a minimum of twice weekly services. Both NGOs offer a range of psychosocial services throughout these districts, although there are no formal bereavement services.

There is no palliative care coverage in the north (including the districts of Kyrenia and the Turkish Cypriot areas in Nicosia, Famagusta and a small area of Larnaca).

### Palliative care workforce capacity

The Cyprus Anti-Cancer Society: As of 2005 the Society employs around 69 full- and part-time health professionals, 18 administrative staff, 10 kitchen and cleaning staff; including at the Arodaphnousa Hospice:

**Table 4.4 Palliative and supportive care in-patient services in Cyprus**

Facility	Service	Provision
Arodaphnousa Hospice	Specialist palliative care unit	18 beds
Oncology Unit: Nicosia General Hospital	Pain and symptom relief	22 beds
Bank of Cyprus Oncology Center: Nicosia	Pain and symptom relief	30 beds
Oncology Unit: Limassol Hospital	Pain and symptom relief	Inpatient facility on general ward
AIDS ward: Larnaca Hospital	Symptom relief	6 beds

one medical director, one physician, 24 nurses, one social worker, one physiotherapist, one aromatherapist, one volunteer reflexologist. The Society employs two full-time and five part-time psychologists to work across all their services. The home care team is supported by hospice staff and in addition employs 13 nurses including a senior nurse, and a nurse coordinator. Volunteers support day care services.

The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF): as of 2005 the Association employs around 53 staff, with 13 administrative staff and 40 full- and part-time health professionals (three physicians, nurses, social workers, psychologists, physiotherapists). Each of the five home teams has four nurses. Volunteers support all services.

### *National and professional organizations*

The Cyprus Anti-Cancer Society was established in 1971. In 1976 the Society established the Arodaphnousa Hospice in Nicosia, which was dedicated to nursing patients dying of cancer. From late 1991, the organization started to offer home care, through the services of hospice nurse, Neophyta Kouppi, who had completed a palliative care training course at St. Christopher's Hospice, UK. Over the last 10 years hospice staff have developed a multi-professional palliative care team, including five separate teams for a daytime home care service and a lymphoedema clinic. In 2000 the hospice was officially recognized as a palliative care center. Through the hospice, the Society has developed and now funds the 18-bed inpatient service, the home care service, and since 1998 has opened day care centers in Nicosia, Limassol, Paphos and Famagusta (17). The Society funds public education programs such as the "Non-smokers League," "Quitline," a call-in stop smoking service and also a stop smoking clinic, and supports public lectures on cancer prevention. It also funds specialist training and education for health professionals working in palliative care and oncology in Cyprus.

The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF) was founded in 1986 by anesthetist Dr. Anna Achilleoudi, who was herself a breast cancer survivor, together with a small group of women dedicated to "the improvement and safeguarding of the quality of life of cancer patients and their families." (18) In 1992 the Association was keen to develop palliative care by setting up a home care service, and employed Jane Kakas to start the first team, based in Nicosia. Through the combined efforts of many health professionals and administrators, the Association has since funded the development of offices in five districts around the Greek Cypriot south, from which they run teams for home care, day care and psychosocial support. The three aims of the Association are:

- to promote awareness about prevention and early detection

- of cancer to the public; for instance, publishing leaflets about having regular checkups and healthy eating;

- to educate health professionals in cancer care and palliative care;

- to provide patient services such as home care for cancer patients, over the age of 16, at any stage of the disease.

There is also a small organization called "Friends for Life" in Limassol, whose members plan to raise funds for a new hospice and day care service in the area. (19)

### *Education and training*

Both the cancer NGOs in Cyprus see education and training as an important part of their work. Both, for example, are members of the European Association for Palliative Care (EAPC) and encourage their staff to attend EAPC conferences and training programs. A recent series of lectures, organized as a combined NGO effort to disseminate the Council of Europe Recommendations for Palliative Care, attracted a total of 220 local health professionals.

In the last five years the Cyprus Anti-Cancer Society has funded two physicians to complete Masters in Palliative Medicine courses in the UK. In recent years three nurses have completed specialist palliative care training, although only one nurse has stayed on working with the Society. There is now a two week introductory placement in the hospice for all second or third year student nurses at the School of Nursing in Cyprus. The Society is committed to encouraging its entire staff to take part in training, some at seminars provided by the hospice, but it also funds travel to international conferences or scholarships to complete specialist courses, such as Diplomas in Palliative Nursing. Sophia Pantekhi explains:

"We try, every year, to encourage our staff to attend courses related to palliative care. For example, every year we organize a two day seminar on psychosocial oncology. We have had courses on lymphoedema treatment. Our staff attends seminars in Athens and a few members of the nursing staff try to attend the hospice program in St. Christopher's, either the multi-professional week or the three-week program. Every year we have, with the cooperation of the oncology department, had a closed workshop for the support of the staff to prevent burnout." (2)

The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF) funds training programs, such as distance learning courses in palliative care at the degree and diploma level for doctors and nurses. The Association also organizes short seminars and conferences. Since 1999, the Association has also funded specialist training courses for doctors, nurses, and physiotherapists in different aspects of

palliative care such as pain relief, wound management, and lymphoedema care, as well as short courses in psychosocial, communication, and bereavement issues, symptom control, and breast cancer. The Association also has links with the School of Nursing in Nicosia. Jane Kakas:

“The School of Nursing has recognized our work, and they send us their training community nurses, who are doing on a postgraduate one year community nursing course.”

To date three courses have run with around 26 students in each year, but as Jane notes:

“None of them have actually gone into the community; they’ve all gone back into the hospital because there is no infrastructure. So they’ve been sending us for the last three years their nurses to spend time working with us, so at least they can see an aspect of community care. It’s very experiential learning for them; we don’t have the backup for such training in a very organized fashion. We might organize a bit of a study day on grief and bereavement or a pain lecture for half a day, but it’s very informal. However, they get the experience of community nursing. We try and place them in the community actually with the home care nurse for anything from 3-6 days, that’s all we can offer. We sometimes offer a day with the lymphoedema service and a day with a psychologist.” (9)

Both NGOs express the need for an expert committee to work with the government in planning and developing palliative care services and to lobby for policy development. In particular, they would like to see policy which allows provision of the full range of palliative care services in government-funded hospitals, available to all patients with other life threatening illnesses (20).

### Ethical issues

Both Greek and Turkish Cypriot communities have a strong tradition of family support. When a relative falls ill, the family will care for them and has, in the past, always tended to protect the relative from bad news. Until the 1990s, the issue of whether or not patients knew their diagnosis and prognosis presented difficult ethical dilemmas for those involved in palliative care. However, partly as a result of improvement in cancer survival rates, which reduces the fear of cancer, and partly because of more support for the patient and their families there has been a significant shift in attitudes; over time, patients and their families have become more willing to speak openly about their illness. As Neophyta Kouppi describes:

“There are families actually, they need to protect the patient, and they visit the oncologist before and they say ‘please don’t tell my father his diagnosis, tell everything to me.’ You know they want to protect the patient, so

they stop the doctor giving information. But if I go back and think about the time we started till now, there are big changes, big steps. Now more patients know about their illness and they know their prognosis and they do things before they die, and they speak more openly.” (3)

Marie-Christina Tchopourian agrees that there have been great changes since 1999 when she started work in the hospice:

“I’ve seen a change in the way they speak with their families about this issue. Before it was much more difficult, there was more of an act around this issue. Now I think people are a bit more honest. I think a lot of it has to do with our doctors changing, and informing the patients about their condition, instead of hiding information like they used to. On the other hand, the patients are more ready now to talk about these issues. The families are not always so ready, and at times we work with the families to prepare them to talk with the patient. Ten or 12 years ago, you would rarely hear the word cancer being mentioned, it was always referred to with other names: that’s changing radically. Part of the reason for that is that the doctors are changing; another big part is all the patients that are surviving cancer. Because Cyprus is a small community, these things are easily made known: that this person had cancer but is OK now, so people are less afraid.”

Marie-Christina Tchopourian identifies the biggest ethical problem now: how much information a patient has. She explains:

“The biggest problem a psychologist faces is when we know more information than the patient, because we really ask the patient to be honest and we are expected to be honest. It really puts us in a difficult position to know more about their illness than they know because they often ask. It’s not a psychologist’s job to inform a patient about their illness or prognosis, but the ethical issue lies in the fact that we work to develop a trusting relationship and it feels unethical to know and act as if we don’t know. Encouraging a more honest relationship between the doctors and patients might solve some of the problem. But, still I think there might be points where the doctor is reluctant to reveal to the patient a poor prognosis, for example. Yet they would openly share it with the multi-disciplinary team. Other members of the team might face the same difficulty, but a trusting relationship might not be so crucial for their job, as it is for a therapeutic relationship between psychologist and patient. A psychologist is expected to really be there.”

The different ways people relate to spiritual attitudes seem to have influenced and been influenced by more open discussions about death and dying. As Barbara Pitsillides affirms in her 2003 report on palliative care in Cyprus, there is a great diversity in beliefs and values of patients

and their families (22). Neophyta Kouppi comments:

“We have a priest from the Greek Orthodox church in the hospice. For the other people who come here, like Turkish Cypriots or people from Sri Lanka, Russia or other religions, we always encourage them to bring their own spiritual representative, their own religion if they want to talk, or to have any kind of service, and we try to give them a single room so they can have their privacy. I think people speak more openly now; even if they don’t believe in any god, there is something more, life after death. They are more open, and they talk more about their family problems, like for example, if they have a child at home who is sick and probably the mother is anxious who is going to take care after her death, or if they feel angry with somebody from the family, then they talk more openly. So people from our multi-disciplinary team can help. We can bring in family members and we can help them find solutions for their anxiety.” (3)

## HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

### Narrative history of palliative care

In Cyprus specific care for cancer patients at the end of life started to be established in the mid-1970s, initiated by the Cyprus Anti-Cancer Society, whose founder members recognized a need for support in the population. As Neophyta Kouppi, now the Matron at the Arodaphnousa Hospice, Nicosia, explains, in the early days:

“Few people in Cyprus knew about hospice and palliative care. We started because we wanted to help the cancer patients to have somebody to care about them. Because after the Turkish invasion and all the problems we’d had in the general hospital with refugees with cancer and nobody to look after them and all those problems, we thought we needed to build a home for them and take care of them. But we didn’t know about hospice philosophy. Later on, we heard about hospice care and that was after, I think, the second meeting in London with Cicely Saunders. One of our members, Dr. Soulitis, an oncologist, heard about St. Christopher’s, so he went there to visit and he returned with many ideas about hospice care and how to control pain and symptoms. So we started to do more things actually about pain, with medicine; for example, to give medications regularly, so as not to be in pain. After a few years we helped the families to spend time with the patients, and encouraged them to go home on weekends, you know, to spend time with their family. But we didn’t know that this kind of care is hospice care.”

By the beginning of the 1990s, there was increasing awareness of the concepts of palliative care. Both organizations, Cyprus Anti-Cancer Society and The

Cyprus Association of Cancer Patients and Friends (PA.SY.KAF), independently recognized the need to develop home care services. Neophyta Kouppi describes her early work setting up the home care service as part of her role in Arodaphnousa Hospice:

“From the end of 1991 in November, I started to visit the Oncology Department in the general hospital and meet the patients who had finished their treatments and were going home. I used to visit the Oncology Department twice a week in cooperation with the oncologist to meet the patients and their families. I gave them information about the home care we could offer them. After their agreement we would start visiting them at home.” (3)

Within a year she had started to enlist more help from two other nurses and had engaged medical support from the hospital oncologists, who prescribed medication to be taken at home. She encouraged the Society to develop services in more districts of the island, initially in Limassol. By the end of the 1990s, services had been extended to four of the five Greek Cypriot administrative districts.

In 1992, Jane Kakas had started to set up the first independent home care team, at the instigation of PA.SY.KAF, in Nicosia. Since this time both NGOs have developed teams in all five Greek Cypriot districts. One important innovation developed by PA.SY.KAF has been the “DITIS” computerized patient record system, which allows the home care team to access a central patient record by internet or mobile. Although still in early stages of implementation, the aim is for all members of the team to be able to share and communicate with each other anywhere on the island and adjust records or discuss problems as needed (23). About 35% of cancer patients now die at home with support from home care teams provided by either Cyprus Anti-Cancer Society or PA.SY.KAF.

Since the late 1990s, both NGOs responded to the need to have dedicated full-time physicians in their services, by funding specialist training. For instance, in PA.SY.KAF one part-time physician has completed a Master’s in Palliative Care and another part-time physician has completed a Diploma in Palliative Care. In the Cyprus Anti-Cancer Society, two full-time physicians have completed a Master’s in Palliative Medicine in the UK.

Psychosocial support has been increasingly prioritized by both NGOs. In 1996 the hospice staff requested that the Cyprus Anti-Cancer Society employ their first social worker. In 1999 the Society appointed its first full-time psychologist, Marie-Christina Tchopourian. She explains the ways the psychosocial staff now work:

“We are two full-time psychologists and five part-time,

covering all the Greek Cypriot districts. The hospice I would say is about 30% of my work. The oncology centers in Cyprus don't have a position for a psychologist, so the voluntary organizations cover the patients' needs. In the hospice, if the team and the doctor feel it would be beneficial, we meet with the patient or their family. At the beginning, there were only a few referrals, but now it's the majority of the patients we have here. We also do home visits, working with patients cared for by the home care teams, other nurses, and the oncology centers, so a patient can meet with us at any point in their treatment, either at home, in the hospice, the oncology centers or at our offices. The same psychologist will stay with the patient throughout the different stages of their disease." (21)

### Hospice success stories

The Arodaphnousa Hospice was established in 1976 by the Cyprus Anti-Cancer Society initially as a nursing home for patients dying of cancer. For the first 20 years the hospice was run entirely by nurses. In 1991, inspired by the UK hospice movement, the Matron, Neophyta Kouppi, attended a course in palliative care at St. Christopher's Hospice in London. On her return, she encouraged the Society to develop a dedicated palliative care team. By the mid-1990s they had well-established links with oncologists who would make weekly visits and advise, prescribe and adjust medications. The nurses, led by Neophyta Kouppi, ran the inpatient unit and provided home care, often working long hours in remote areas of the island. In 1996, the Society employed a social worker, who could develop much-needed psychosocial services, and in 1999 employed a full-time psychologist.

In 1998, the Society funded a scholarship for Dr. Sophia Pantekhi to take a Master's in Palliative Medicine at Glasgow University, UK. She returned in 1999 to take the first full-time post of Medical Director for the hospice. Since 2002, the Society has been able to fund the specialist training and full-time post of a second physician, Dr. Eleni Karatzia, who is now working with the Medical Director. By 2000, the hospice had gained recognition as a palliative care center, able to provide palliative care education, with a multi-professional team. A purpose-built conference room and library is currently being completed at the hospice.

Arodaphnousa Hospice has increased the numbers of patients treated by supporting more people to be discharged back home, once their symptoms are controlled, and to receive care from the home care team. As Sophia Pantekhi explains:

"We're trying to keep the patients at the hospice no longer than 14 days depending on their need for pain and symptom control, complementary therapies and whether

the family need support with respite care. In the past they just leave the patients to stay here for months and a few of them for a year. We have increased the discharge of patients: we refer them to the home care service." (2)

Neophyta Kouppi relates the success of the home care service and how it developed from a clear response to the need of patients:

"I found ladies crying in the sitting room of the Oncology Department, not because the husband has cancer or because he was going to die, but because they couldn't help him at home and the doctor had said, 'You have to take him home, we finished treatment.' And that was very difficult for the family. So I wanted to do something and I was very enthusiastic. I wanted to do many things for cancer patients and I thought that first to go to their house and help them and then they will trust me and trust Cyprus Anti-Cancer Society, and slowly, slowly we changed things, especially with the oncologists. I believe that when they saw the benefits from visiting the patients at home the oncologists were willing to improve cooperation with us. Gradually we started to employ nurses in other districts too, and I used to work here and go round the districts and help the nurses, and slowly we start to cooperate with the local doctors in districts with the social workers, and with the government Welfare Office about economic problems and other problems. And we asked the psychologists from the government services to support patients. Now the Cyprus Anti-Cancer Society employs social workers, psychologists and their own doctors. Now things are much better and easier." (3)

### LIFE/ORAL HISTORIES

**Neophyta Kouppi—Matron: Arodaphnousa Hospice, Nicosia: interviewed by Amanda Bin-gley, 8 March 2005—duration of interview: 35 minutes**

Neophyta Kouppi relates how she was the first member of staff to work in the Arodaphnousa Hospice when it was a nursing home, before the Cyprus Anti-Cancer Society knew about specialist palliative care:

"I started with general nursing in the government hospital. But as soon as this hospice was started in 1976, I came here before the patients actually, after the builders went away. Well, I didn't know anything about hospice by that time. Later on in 1991 I heard about hospice care and I went to London for a Master's, and then to St. Christopher's for the training course 931: 'The Care of the Dying and Care of Family.'"

With renewed confidence in her skills, following this specialist training, Neophyta describes how she single-

handedly and with great dedication started extending services beyond the inpatient nursing home. From 1991 she started nursing patients in their own homes and through this work set up the first home care team from the hospice, providing care in the Nicosia area. She went on to set up further teams in four other districts around the island. She is now Matron of the 18-bed inpatient unit at the hospice, and over the last ten years has promoted the development of psychosocial and day care services.

**Dr. Sophia Pantekhi, Medical Director: Arodaphnousa Hospice, Nicosia:** *interviewed by Amanda Bingley, 2 February 2005 – duration of interview: 37 minutes*

Sophia Pantekhi speaks of how she was invited to start working as Medical Director in the Arodaphnousa Hospice. In 1998, after having completed her specialty in internal medicine, she applied for a scholarship offered by the Cyprus Anti-Cancer Society to do a full-time Master's in Palliative Medicine at Glasgow University, UK. At the instigation of oncologists Dr. Helen Soteriou and Dr. Adamas Adamou, the Society was seeking a specialist, full-time Medical Director at the inpatient Arodaphnousa Hospice. Having completed her Master's in 1999, Sophia returned to take up the position of Medical Director. She has encouraged a number of important initiatives at the hospice, including the training of a second doctor, Eleni Karatzia, who is completing a Master's degree from Kings' College, London, and began work at the hospice in 2003. With the help of other staff, Sophia has overseen the continuing development of psychosocial services, including art and music therapy; new support services for staff; and improvements to the home-care service so patients can have more options to transfer back to their own home if they wish. Sophia has worked hard to develop training for health professionals at student, postgraduate and professional level. She is keen to work towards an integrated palliative care service available within government hospitals and to develop services for all patients at the end of life, regardless of their illness.

**Maria-Christina Tchopourian, Psychologist: Cyprus Anti-Cancer Society, Nicosia:** *interviewed by Amanda Bingley, 10 March 2005 – duration of interview: 35 minutes*

Maria-Christina Tchopourian speaks of how she came to be involved in palliative care:

"I studied psychology, and then when I did my Master's I did 'thanatological' counseling, specializing in death-related issues and people with chronic diseases: cancer, AIDS, any disease that's considered chronic. So that was my early interest. At the beginning I was more interested

in bereavement and death, but gradually I realized that palliative care could be implemented and I could help people not only at the end of their life but throughout the course of the disease. So I decided that this was what I really wanted to do."

She applied for a job with the Cyprus Anti-Cancer Society, and in 1999 was employed full-time as the Society's first psychologist. She now works with one other full-time and five part-time psychologists and three full-time social workers providing psychosocial support for patients at home, in the hospice and in the oncology centers.

**Jane Kakas - Clinical Nurse Specialist, Home care service, The Cyprus Association of Cancer Patients and Friends (PA.SY.KAF):** *interviewed by Amanda Bingley, 8 April 2005 – duration of interview: 75 minutes*

Jane Kakas talks about becoming interested in palliative care from her early nursing days:

"When I worked as a nurse, as a surgical ward sister in the UK, we used to get a lot of referrals from GPs that were patients who were perhaps end stage, into our ward, and I got interested there in pain management and care of the dying. Then when I went to live in Cyprus, I worked in a private hospital where there was little knowledge of pain management. I felt very distressed and frustrated and left as I had an opportunity to go to the UK for a short period. I looked for a relevant course which would benefit my work in Cyprus and luckily got a place on the Care of the Dying 931, the ENB course and I did that at Epsom, at Princess Alice Hospice at Esher. And it was just the nicest six-week time I've had: it was so enjoyable and I learned so much. When I came back to Cyprus I was introduced to the current president of our Association – the Cyprus Association of Cancer Patients and Friends – and she said, 'let's meet and see what we can do, we want to start home care.' So in 1992 I went to this Association, had an office - I didn't really know what to do with it, I didn't know where to start - but I started to do home care in Nicosia. In 1995, I did the two-year, distance learning diploma in pain management at the University of Wales, College of Medicine, in Cardiff. I feel quite passionate about pain and the concept of suffering. I have done my best to share any knowledge with my colleagues and they are all excellent at pain and symptom control, so it was well worth it."

After quite a few years in home care, Jane helped organize the use of a wider range of opioids. She is currently working towards developing national procedure and policy for palliative care. Although there is no primary medical care system or community nursing service in

Cyprus there are plans to develop policy and procedures for registered nurses in the community, with a new community nurse training in place. In the last year a pilot study has been set up in a small area of Nicosia, with two nurses working in the community. Jane Kakas at PA.SY.KAF has been asked to jointly help write the policies and procedures with the School of Nursing in Nicosia.

## REFERENCES

Stjernswärd J, Clark D. Palliative medicine—a global perspective. In: Doyle D, Hanks G, Cherny N, Calman K (eds.) Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press; 2003. [www.who.int/cancer/palliative/en/](http://www.who.int/cancer/palliative/en/)

## ENDNOTES

- Throughout this report, in order to avoid unintended misunderstandings, we have used the definitions and nomenclature used by the United Nations to describe the two communities of the Greek Cypriots in the south and the Turkish Cypriots in the north (also referred to in Reports by the Secretary General as the Greek Cypriot side and the Turkish Cypriot side). We may also refer simply to north and south. For details about the history of conflict and the ongoing negotiations towards a peaceful resolution between the Greek Cypriots in the south of the island and Turkish Cypriots in the north see United Nations Peacekeeping Mission in Cyprus UNFICYP website: [www.un.org/Depts/dpko/missions/unficypr/index.html](http://www.un.org/Depts/dpko/missions/unficypr/index.html).
- IOELC interview: Sophia Pantekhi - 2 February 2005.
- IOELC interview: Neophyta Kouppi – 3 March 2005.
- Information from Cyprus Anti-Cancer Society: [www.anticancersociety.org.cy](http://www.anticancersociety.org.cy) – as of 10 June 2005.
- The terms *supportive care* and *palliative care* (or palliation) are used to denote both different approaches to stages of treatment and illness, as well as the intention of care. There are a number of definitions in current circulation and some literatures use the terms interchangeably. We are following definitions of the care, generally considered appropriate to different stages of illness, broadly in accordance with the European Society of Medical Oncology (ESMO) where *supportive care* is all care at all stages of illness, *palliative care* is care when no cure is possible, and *end-of-life care* is care when death is imminent. [www.esmo.org](http://www.esmo.org).
- Malas S. From Cyprus. *Palliative Medicine* 2003;17:150. [Dr. Simon Malas is a specialist in oncology and palliative medicine, Department of Oncology, Nicosia General Hospital.]
- Costello J and Christoforou C. Palliative care in a Mediterranean culture: a review of services in the Republic of Cyprus, *International Journal of Palliative Nursing* 2001;7:286-289.
- Bank of Cyprus Oncology Centre [www.bococ.org.cy/english-pdf/english.pdf](http://www.bococ.org.cy/english-pdf/english.pdf).
- IOELC interview: Jane Kakas - 8 April 2005.
- IOELC interview: Raziye Kocaismail – 3 August 2005.
- Information about the Kemal Saracoglu Anticancer and Anti-leukemia Association: [www.hri.org/news/cyprus/tcpr/2003/03-08-26.tcpr.html](http://www.hri.org/news/cyprus/tcpr/2003/03-08-26.tcpr.html).
- Amounts given in local currency: Conversion rate into Intl \$ at June 2005: CY£ 1 = \$2.09.
- The Cyprus Anti-Cancer Society budget information for 2003.
- Pitsillades N. Palliative care in Cyprus, *Hospice Bulletin*, December 1995.
- Ministry of Health, Cyprus: Medical Card General Regulations and Application for a Medical Card as of 10 June 2005 [www.moh.gov.cy/moh/moh.nsf/medcard\\_en/medcard\\_en?OpenDocument](http://www.moh.gov.cy/moh/moh.nsf/medcard_en/medcard_en?OpenDocument).
- Kakas J and Pitsillides B. Managing cancer pain at home: the experience of Cyprus [www.whocancerpain.wisc.edu/eng/10\\_2/cyprus.html](http://www.whocancerpain.wisc.edu/eng/10_2/cyprus.html) (accessed 29/06/05).
- Andronikou A. The Cyprus Anti-Cancer Society, EAPC Newsletter No. 33, December 1998.
- The Cyprus Association of Cancer Patients and Friends information as of 10 June 2005 [www.cancercare.org.cy/EN/](http://www.cancercare.org.cy/EN/).
- Personal communication Kate Kottam 10 March 2005.
- Discussion MECC conference, Larnaca, Cyprus 2-3 February 2004.
- IOELC interview: Marie-Christina Tchopourian – 10 March 2005.
- Pitsillides B. From Cyprus *Palliative Medicine* 2003;17: 121. [Barbara Pitsillides is a specialist palliative care nurse for PA.SY.KAF.]
- Pitsillides B and Pitsillides A. A virtual multidisciplinary team for terminal care, *European Journal of Palliative Care* 2004;11:202-203. (Aspects of this paper have been presented at the following conferences; “Cancer care: focus on cancer pain” at Limassol 28-31 May 1997; 8th Congress EAPC at The Hague, Netherlands, April 2003; High Level Ministerial Conference: eHealth: ICT for Health at Brussels, 22-23 May 2003.) See also Pitsillides A, Pitsillides B, Samaras G, et al. DITIS: a collaborative virtual medical team for home healthcare of cancer patients. In: Istephanian RH, Laxminarayan S, Pattichis CS, eds. *M-Health: emerging mobile health systems*, London: Kluwer Academic/Plenum; 2003.

# Chapter 5

## Palliative Care in Egypt

Egypt (population 76,117,421) is a country in Northern Africa which covers an area of 1,001,450 square kilometers, bordering the Mediterranean Sea, between Libya and the Gaza Strip, and the Red Sea north of Sudan, and includes the Asian Sinai Peninsula. Egypt borders Israel, Libya, the Palestinian Authority Gaza Strip, and Sudan.

The regularity and richness of the annual Nile River flood, coupled with semi-isolation provided by deserts to the east and west, allowed for the development of one of the world's great civilizations. Today, a rapidly growing population (the largest in the Arab world), limited arable land, and dependence on the Nile all continue to overtax resources and stress society.



### PALLIATIVE CARE SERVICE PROVISION

#### Current services

In Egypt, two organizations provide a total of six hospice/palliative care services (Table 5.1). The National Cancer Institute in Cairo offers pain relief and symptom management at the end of life. The Cairo Evangelical Medical Society provides inpatient and day care hospice facilities at the Cairo Evangelical Medical Hospice and at Elhadara Elromany, in Alexandria.

Dr. Naguib Elnikhaily reports on the services at Cairo Evangelical Medical Hospice, developed and opened in 2001:

“At first there were four beds, now 11. We have a waiting list. We may double the number of patients in each room. We also have a home care program: ‘Care with Love’ and two outpatient clinics and are aiming for a day care service.” (1)

In February 2005, inpatient numbers averaged eight to nine. Naguib Elnikhaily has plans for up to three more projects in the southeast of Cairo (2).

In contrast to such individual nongovernment organized services, the emphasis in government hospital oncology units is on the provision of basic pain relief to patients with advanced disease. During 2004, however, palliative care—seen more widely—became included in the oncology nursing program at the National Cancer Institute (NCI) (3).

Egypt has national guidelines for the management of acute pain and chronic cancer pain. Guidelines for symptom management, end-of-life care, and home-based hospice care are currently being developed.

Table 5.1. Palliative care provision in Egypt, 2005

Adult Services							
	Freestanding unit	Hospital unit	Hospital support team	Home care	Day care	Clinic/ Drop-in center	Grand Total
Cairo Evangelical Medical Society ~ Cairo Evangelical Medical Hospice ~ Elhadara Elromany, Alexandria	1 1			1		2	4 1
National Cancer Institute (NCI), Cairo University		1					1
<b>Total</b>	<b>2</b>	<b>1</b>		<b>1</b>		<b>2</b>	<b>6</b>

### Reimbursement and funding for services

The NCI is a government-funded facility. An estimated 65% of patients are treated free of charge; the remainder have health insurance which covers their treatment costs. Cairo Evangelical Medical Hospice provides privately-funded inpatient hospice and home care. Patients are required to cover their own costs, but fees are reportedly kept to a minimum.

### Opioid availability and consumption

The International Narcotics Control Board (4) has published the following figures in 2002 for the annual consumption of narcotic drugs in Egypt: codeine 296 kg (down from 1983 kg in 1998); morphine 5 kg (down from 12 kg in 2000); pethidine 87 kg (up from 30 kg in 1999).

For the years 2000-2002, the average defined daily dose consumption of morphine for statistical purposes (S-DDD) (5) in Egypt was two.

### Palliative care coverage

There are six university-based hospital oncology units around the country committed to providing pain relief. The main oncology unit at NCI, based at Cairo University, is taking the lead to actively develop services within the NCI by building on work in the pain relief units. In addition, there are eight small cancer centers in various parts of the country.

Cairo Evangelical Medical Hospice receives patients from the local area, most of whom are referred by themselves or by family members.

### Palliative care workforce capacity

As of February 2005 no available data exists for numbers of government-funded medical and related professionals specifically involved in palliative care in Egypt.

Cairo Evangelical Medical Hospice has one medical director, one senior nurse, and four assistant nurses (6).

Nursing and medical staff involved in developing palliative care at the National Cancer Institute, Cairo University, are keen to seek government and World Health Organization (WHO) support to initiate a needs assessment (7).

### National and professional organizations

Although there are many NGOs involved in general health care in Egypt, currently none are dedicated to palliative care.

National Cancer Institute (NCI), Cairo University. This government organization is actively engaged in planning and developing services.

The Cairo Evangelical Medical Society, a Christian organization, supports and runs one private hospice in Cairo and another recently opened in Alexandria.

### Education and training

The Eastern Mediterranean Regional Office (EMRO) based in Cairo, as a WHO office aims to promote health in the 22 states of the region, of which Egypt is one. At present EMRO is proposing to develop a training program as part of a plan to promote palliative care services in

these states, since palliative care services remain underdeveloped (8).

A palliative care training program is being developed at NCI, which aims to provide basic training as part of general medical education for doctors, nurses and other professionals (9).

At the Cairo Evangelical Medical Hospice, Naguib Elnikhaily has organized training courses provided by visiting nurses from the UK (1).

### Ethical issues

Egypt has a strong cultural tradition of family support. When a family member is diagnosed with a life-threatening disease the family will assume the care for their relative. However, as Dr. Ahmed Helmy at NCI outlines, in addition to the problem of financial support for providing services there remains a lack of adequate knowledge about the importance of palliative care. Dr. Nagwa Elkateb also explains that there is a great need to educate “families about home palliative care” and not to rush into an inappropriate approach. As she notes, “we have a shortage of nurses; and we need to teach families [about palliative care]. We have a high respect for families.” (10)

As several authors have highlighted in their observations around the world, different cultural approaches to death and dying may present considerable challenges in developing palliative care services that are sensitive to and appropriate for the different communities they serve (11). There is a continuing ethical challenge and debate concerning openly discussing diagnosis and prognosis with patients. For many of the cultural and religious traditions in this region, as in other parts of the world, there is marked resistance to openly discuss with a patient the fact of their imminent death. The family will tend to protect their relative and talk with the medical professionals directly, regardless of whether the patient would wish to know their prognosis and prepare themselves for death (12).

### History and development of palliative care

Palliative care in Egypt is in the early stages of development. For many years the major support for patients with life-threatening illness, most particularly cancer, has been via oncology units specializing in pain relief (13). Tawfik (1993) reports that in the early 1990s he located one clinic focused on training a member of the patient’s family in pain relief with the help of the supporting doctor.

The system of guidelines for pain relief provision and the focus of pain relief in oncology clinics is well-established.

The NCI has led the way in developing pain relief for cancer patients. The NCI was opened in 1969, inspired by cancer specialist Professor Aboul-Nassr and supported by Professor El Sebai. As the largest cancer hospital in Egypt, the NCI was renovated in 1989 with a capacity of 500 beds and a further extension built in 1993 providing a further 230 beds. Pain relief has always been a priority, particularly as the estimated 55,000-65,000 patients with cancer per year “usually present at a relatively advanced stage of their disease.” (14)

Dr. Nagwa Elkateb (Director of Nursing, NCI) reports that at present there is much debate about how and in what form palliative care might become established in Egypt; solutions are still unclear. She explains:

“We have good guidelines on opioids, but we have to assess the needs in Egypt—motivated by the workshop [Larnaca MECC conference, February 2004], but we don’t know the needs. Do we need supportive care, palliative care? Do we start with cancer or other diseases? Maybe we don’t need other hospices? Maybe a terminal care unit in each hospital? (10) There is felt to be a need for some input from experienced international organizations who can offer support and guidance.” (3)

### LIFE/ORAL HISTORIES

Dr. Naguib Elnikhaily describes how he became interested in palliative care after he was treated for cancer at the Cleveland Clinic in the US and saw a hospice unit there. On his return to Cairo he discussed it with the hospital and started the Cairo Evangelical Medical Hospice with only four beds (1).

### ENDNOTES

1. Dr. Naguib Elnikhaily in discussion MECC conference, Larnaca, Cyprus (February 2004)
2. Personal Communication with Dr. Naguib Elnikhaily (February 2005)
3. Personal communication with Dr. Nagwa Elkateb, Director of the Technical Institute of Nursing, NCI, Cairo University (February 2005)
4. International Narcotics Control Board (2004) Narcotic Drugs: estimated world requirements for 2004. Statistics for 2002. New York: United Nations, 2004.
5. ‘The term defined daily doses for statistical purposes (S-DDD) replaces the term defined daily doses previously used by the Board. The S-DDDs are technical units of measurement for the purposes of statistical analysis and are not recommended prescription doses. Certain narcotic drugs may be used in certain countries for different treatments or in accordance with different medical practices, and therefore a different daily dose could

- be more appropriate.’ International Narcotics Control Board. Narcotic Drugs: estimated world requirements for 2004. Statistics for 2002.
6. Personal communication: Dr. Fouad Bekeheit – 20 April 2005.
  7. Personal Communication with Dr. Ahmed Helmy and Dr. Nagwa Elkateb at NCI, Cairo University (February 2005)
  8. Al-Shahri M, Brown S, Ezzat A, Khatib O. (2004) Palliative care initiative for the Eastern Mediterranean Region: a proposal *Ann Saudi Med* 24:6 pp.465-468
  9. Personal Communication with Dr. Ahmed Helmy, NCI, Cairo University (February 2005)
  10. Dr. Nagwa Elkateb in discussion MECC conference, Larnaca, Cyprus (February 2004)
  11. Musgrave C. (1995) “Rituals of death and dying in Israeli Jewish culture” *European Journal of Palliative Care* 2:2 pp.83-86
  12. Gatrads AR & Sheikh A. (2002) “Palliative care for Muslims and issues before death” *International Journal of Palliative Nursing* 8:11 pp. 526-531
  13. Tawfik MO (1993) “Egypt: status of cancer pain and palliative care” *Journal of Pain and Symptom Management* 8 (6) pp.409-411
  14. Khaled HM (2000) “The National Cancer Institute in Cairo” *INCTR Newsletter* 1:20 [http://www.inctr.org/publications/2000\\_v01-n20\\_a11.shtml](http://www.inctr.org/publications/2000_v01-n20_a11.shtml)

# Chapter 6

## Palliative Care in Israel

Israel (population 6,352,117) (1) is a country in the Middle East that covers an area of 20,770 sq. km. It borders the Mediterranean Sea between Egypt and Lebanon, and its land borders Egypt, Jordan, Lebanon, and the Palestinian Authority in the Gaza Strip and West Bank.

The population includes about 187,000 Israeli settlers on the West Bank, about 20,000 in the Israeli-occupied Golan Heights, and fewer than 177,000 in East Jerusalem (2).



### PALLIATIVE CARE SERVICE PROVISION

#### Current services

Eleven organizations offer palliative care for adults in Israel, delivering a total of 27 services mainly for adults via seven home hospices (includes one mobile unit), four inpatient hospice units (three are freestanding units, one is hospital-based) and two hospitals offering inpatient palliative care. About six of these services offer pediatric palliative support (Table 6.1).

In addition to these specialist services, some 80 community health centers provide at home pain and symptom relief for patients at the end of life. Some oncology clinics also provide psychosocial palliative support. There are over 500 oncology nurses in Israel, most of whom have completed a formal postgraduate oncology nursing qualification which includes symptom management and palliative care. About 30 oncology nurses have completed further palliative care training. These nurses work in hospital oncology units or in community health settings; some of those with further training are based in the specialist palliative care organizations.

A National Cancer Control Program (NCCP) for Israel was established during the early 2000s (3,4). A national HIV/AIDS policy was established in the late 1990s (5). These policies include an acknowledgment of palliative care as a component of the management of HIV/AIDS and cancer control. The NCCP has an advisory committee set up to examine palliative care needs (6).

#### Tel Hashomer Hospice (Miriam and Max Freedman House), Sheba Medical Center, Tel Aviv

TelHashomer provides end-of-life care and support to cancer patients and their families (7). The hospice is situated at the Chaim Sheba Medical Center, a large regional 1,563-bed hospital. The hospice, founded in 1983 by Dr. Marian Rabinowitz (8), was the first specialist palliative

care service to be established in Israel. The service has developed an interdisciplinary team (physicians, nurses, physiotherapist, social workers, clinical psychologist and spiritual counselor) who are particularly experienced in offering specialist pain and symptom relief, together with psychosocial care and physiotherapy. The service includes:

a purpose-built, 22-bed inpatient unit (staff and patients moved into the new building from the original, older facility in 2003),

a home care team providing 24-hour care for up to 25 patients from within a 25 mile radius from the hospice

a palliative care outpatient clinic at the oncology department of the Sheba Medical Center.

The service is based on an ethos of providing the best quality care at the end of life in a tranquil environment with adequate symptom management and support, but with as little intervention as possible (8). The service does not encourage unnecessary tests, or routine use of oxygen or antibiotics (7). The average duration of care is 16–18 days. Patients are referred by their physician or oncologist – dependent on approval from the Medical Center's health insurance provider (9).

### Ina and Jack Kay Hospice, Hadassah Mount Scopus, Jerusalem

The hospice, founded in 1986 by Dr. Theodor Fink and Ruth Gassner RN, MA, and situated in the grounds of the 300-bed Hadassah Mount Scopus Hospital, provides end-of-life care and support to adults with cancer and their families. Working as a multi-professional team (physician, nurses, social workers, physiotherapist and occupational therapist) under the directorship of Ruth

Table 6.1: Palliative care provision in Israel, 2005

	Freestanding unit	Hospital unit	Hospital consultation	Pediatric support	Home care	Day care	OPD clinic	Drop-in center	Grand Total
Tel-Hashomer Hospice, Sheba Medical Centre	1				1		1		3
Ina and Jack Kay Hospice, Hadassah, Mount Scopus	1				1				2
Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center		1	1			1	1		4
Hannah Eshed Hospice, Nof Hadar Hospital, Haifa	1								1
Negev Palliative Care Services ~ home hospice ~ desert mobile unit ~ hospital consultation service ~ Ma'agan House			1	1	1 1			1	5
Milton and Lois Shiffman Home Hospice in the Valleys					1				1
Home Care Hospice of Kiryat Tivon					1				1
Jerusalem Home Hospital				1	1				2
Nancy Caroline Hospice of the Upper Galilee					1				1
St. Louis Mission, Jerusalem		1							1
Italian Hospital, Haifa		1							1
Edmond and Lily Safra Children's Hospital				1					1
Meyer Children's Hospital				1					1
The Marion and Elie Wiesel Children's Pavilion		1		1					2
Schneider Children's Medical Centre				1					1
<b>Total</b>	<b>3</b>	<b>4</b>	<b>2</b>	<b>6</b>	<b>8</b>	<b>1</b>	<b>2</b>	<b>1</b>	<b>27</b>

Gassner, the service offers specialist pain and symptom control, physiotherapy, occupational therapy and psychosocial support. A part-time art therapist also attends the hospice at various times (10).

The hospice service includes:

- a 14-bed inpatient unit (renovated in 2004)
- a home care service providing 24-hour care for up to 20-25 patients
- links with the charitable organization Yad Sarah that lends nursing and home care equipment (hire is free or in exchange for a donation).

In 2003, the inpatient unit cared for 170 patients. Fifty patients were cared for by the home care service which provides 24-hour nursing care from a team of nurses working from the hospice (11). The hospice has developed a highly individualized service with dedicated and skilled psychosocial support led by social worker Malka Yehezkel. The team also works with trained volunteers who are able to offer general support to patients and their families. The social worker and other team members provide opportunities from the first assessment for patients and families to share anxieties and discuss concerns with hospice staff. Families are encouraged and supported to be involved in their relatives' care equally at home or in the hospice unit. Members of the hospice team (the senior physician and home care nurses) run a counseling support service for patients in the hospital who transfer to the hospice. The hospice also offers bereavement support.

Part of the palliative care in this service includes maintaining varying degrees of medical intervention. For instance, senior physician and researcher Dr. Daniel Azoulay may, in addition to pain relief and symptom management, also prescribe antibiotics, oxygen and subcutaneous fluids, if appropriate (10). Patients or their families can self-refer, or they are referred by staff in a hospital unit, or by their family physician or oncologist (12).

### **Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center, Jerusalem**

The Cancer Pain and Palliative Medicine Service, established in 1994, is part of the oncology unit at Sha'are Zedek, a large 500-bed medical center in Jerusalem. The diverse, multi-professional, multi-lingual team includes physicians, general and oncology nurses, a research coordinator (who is also a clinical pharmacologist), social workers, a spiritual counselor and a consultant psychiatrist. The team offers integrated oncology and palliative

care, including spiritual counseling to adult patients with cancer. The service has:

- an outpatient unit
- a day care service
- a 22-bed inpatient unit (opened in 2003)
- inpatient consultation service.

The inpatient unit was opened for the acute management of hematology and oncology patients and for those in need of palliative care. Dr. Nathan Cherny, Director of the Palliative Medicine Service, explains:

“The average census is that there will probably be about 12 palliative care inpatients at any one time. The sorts of problems that are dealt with are acute symptom control problems, patients who are imminently dying, patients who are not coping at home but are not imminently dying. We will generally stabilize them and in most cases pass them on to the hospice or the French Hospital. Occasionally they will stay with us until they die.” (13)

In 2004 a full-time spiritual counselor, Jonathan Rudnick, joined the Service and his role in the team has proved successful for many patients whether they are religious or secular, and is felt by staff to have provided a very positive contribution to the Service's overall ethos of supporting the whole person (14). The Service provides palliative care for around 500 new patients per year, seeing around 1000 patients per month, of which a third require palliative care. Patients are referred to the palliative care services by oncologists within the unit and from other departments.

### **Negev Palliative Care Services, Beersheba**

Negev Palliative Care Services is a multi-disciplinary team (physicians, nurses, social workers) offering specialist pain and symptom relief and a range of psychosocial support for adults and children with cancer (15). It was established in 1991 as a home-care service for adults in the city of Beersheba. In 1994, a more extensive home-based service was initiated and a hospital consultation service developed for adults (16). Since the establishment of the children's oncology unit at Soroka Medical Center in 1999, the service also offers inpatient palliative care consultation for children.

Based in Beersheba, the only major city in the south of Israel in the Negev desert, the service has to serve a large multi-cultural population dispersed over hundreds of miles

(17). The organization has responded to this challenge by developing several different multi-professional services including:

three home care teams working over a wide area from different urban locations

Beersheba: up to 24 patients

Qiryat Gat: up to 46 patients per year

Rahat: between 4-6 patients (up to 14 per year)

a mobile desert unit (set up in May 2004): up to 26 patients

a bereavement service based in Beersheba and run by trained volunteers

Ma'agan House, a charitable drop-in day center, situated in Beersheba; this center offers psychosocial support including therapy support groups, art and music therapy

a hospital-based adult and pediatric palliative care consultation and support offered at the only regional hospital, the 1,000 bed Soroka Medical Center in Beersheba (18).

The home care teams offer 24-hour support. Each year, the teams care for around 140 patients at the end of life. Roughly 78% of these patients are able to be supported to die in their own home. Seventy per cent of those who die in hospital are only admitted in the last 24 hours of life. Admission to the home care service is based on three criteria, as Medical Director Dr. Yoram Singer explains:

“There must be a main caregiver, so the patient is never alone and he must be in such a situation that he can't get his medical care in the local clinic. He has to be more or less housebound. Average duration of treatment is 47 days, so we're really talking about the very end.”

The hospital consultation service is accessible to all patients in Soroka Medical Center, Beersheba: they have either to be referred by their physician or oncologist, or they or their family may request referral. Dr. Singer reports:

“This year [2004-2005] I've seen about 450 patients. I see patients at the oncology daycare and I get called to the various wards to give consultations... Many services are supported by volunteers; for example, the bereavement service—currently being developed—is organized

by social workers with a large group of trained volunteers.” (15)

Patients may self-refer to one of the three home care service teams, or be referred by one of the hospice service oncologists following a hospital consultation, or be referred by their own physician or oncologist from another department. The home care service has strong team support for permanent and student placement staff (family medicine trainee physicians). The team convenes once weekly for report and supervision meetings and senior team members provide 24-hour on-call advice.

### Milton and Lois Shiffman Home Hospice in the Valleys

The hospice, founded in 1999, provides home-based specialist palliative care including pain relief, symptom management and psychosocial support for adults at the end of life regardless of their illness, although the majority have cancer. The hospice has focused on developing a service sensitive to a culturally diverse, multi-religious population (19). For example, in Arab Nazareth the team may include a Jewish physician, Muslim nurse, and social worker, and Arabic-speaking Jewish nurses with additional support from Christian and Muslim volunteers and clergy (20). The hospice service includes:

Seven multi-professional, culturally diverse, multi-lingual teams (each with supporting physician, nurses and social workers): providing care for up to 45 patients at any one time

good links with local community health centers

strong support of trained volunteers

palliative care training programs for primary health care providers

on-call consultation services for community health care clinics in the area.

A total of 162 patients were cared for in 2004, for an average duration of 60 days. Since 1999, the hospice has cared for around 600 patients. The emphasis is on supporting patients and families to cope with the end-of-life process; hospice staff will educate caregivers and also undertake to stay with patients and their families as long as they are needed (21). Around 74% of patients are supported to die at home. Hospice Director Mali Szlaifer explains:

“When you give [the family] good education—and also if you give them some tips what to do to feel better, so they can manage with [the patient] they are not afraid and they feel comfortable, confident in being there and they know that now it’s not an emergency.” (22)

Patients can self-refer but more usually they are referred by their physician or oncologist. The hospice has also developed strong support for its staff. There are regular team meetings, group supervision (plus individual if needed), and 24-hour on-call advice from senior team members.

### Jerusalem Home Hospital

This large organization, established in 1991 and run by health maintenance organization (HMO) Clalit Health Services (Kupat Holim Clalit) (23), offers community-based “home hospitalization” for patients, the majority over 65 years old, suffering a range of subacute and chronic illnesses, including cancer, renal and heart failure, and ALS. The service provides treatment, rehabilitation, and for patients at the end of life, specialist palliative care (24). The service will also support young people and children at the end of life. The multi-professional team (physicians, specialist oncology nurses, nurses, physiotherapists, social workers, nutritionist, occupational and speech therapists) is led by geriatrician Dr. Jeremy Jacobs and palliative care consultant Dr. Ora Rosengarten. The service offers pain relief, symptom management, physiotherapy, psychosocial support, occupational therapy, speech therapy, nutritional advice, and home help. The service currently cares for around 300 patients at any one time. Roughly half of all patients admitted to the service are palliative care patients and on average 30% of these have cancer. The criteria for admission to the service include:

Diagnosis is clear, but the patient no longer needs continuous monitoring

The patient is in need of hospital-level care

The patient and family must both agree to home-based care

There must be a supportive caregiver for the patient at home (not necessarily a family member)

The patient’s home is a suitable environment in which to nurse the patient

The patient is insured with the Kupat Holim Clalit.

The aim is to reduce hospital admission and maintain a high quality of total care for patients at home. Around

50% of palliative care patients are supported to die at home or within 24 hours if admitted to hospital in the last hours. Since the service was established it has cared for over 13,000 patients (24).

### Nancy Caroline Hospice of the Upper Galilee (HUG) Hospice of the Valleys

This hospice is a specialist, not for profit, home care service primarily for adults with cancer. The hospice was founded by Professor Nancy Caroline in 1994. She herself became ill and died in 2002. Since 2001 the multi-professional team has been led by Medical Director Dr. Jim Shalom. The hospice provides pain relief, symptom management, physiotherapy, nutritional advice and dedicated psychosocial support.

The hospice is committed to highly individualized care with the focus on a holistic approach. The multi-professional team (physicians, specialist oncology nurse, nurses, social worker who is also a family therapist, clinical psychologist, art therapist, music thanatologist—a harpist) are attentive to skilled symptom management but also to supporting a patient’s emotional and spiritual needs, drawing particularly on the use of creative therapies. House calls are typically made by a physician and nurse together. Rather than replace existing services, the HUG team coordinates care with both the primary care team and the regional Oncology Department. Trained volunteers are an important part of the team, offering personal support and assistance to the patient and families when requested. The hospice staff is equally involved in training volunteers.

As of 2005 the service can care for up to 35 patients at any one time, and the service is being expanded to increase care capacity. Patients are self-referred or referred by their physician or oncologist. Around 70-80% of patients are supported to die in their own home.

### Home Care Hospice of Kiryat Tivon, Northern Israel

The hospice is a small not-for-profit home care service for adults living in Kiryat Tivon with cancer at the end of life; it is run by volunteers. The hospice was co-founded in 1983 by sociologist Dr. Ilene Ora Cibulski and other multi-professional colleagues. Dr. Cibulski is also a founding member and first chair of the Israeli Association of Palliative Care. Under her direction the hospice developed an emphasis on providing practical support for the patient and their family that includes:

coordinating volunteer professional medical, nursing, therapeutic, and psychosocial support (the

patient continues to receive care from their hospital physician and oncologist)

arranging support from trained volunteers who as “friendly visitors” offer:

home help

social support

help with child care

collection of prescriptions

cooking, shopping or other special needs

hospice volunteers who provide a telephone information helpline for families living outside Kiryat Tivon

support to other organizations around Israel to develop volunteer groups

links with the other charitable organizations:

the Association of Services for the Elderly

Yad Sarah, that lends nursing and home care equipment (free or in exchange for a donation)

The hospice head nurse and social worker evaluate the needs of the patient and family caregiver, and they coordinate the visits of the volunteer multi-professional team members (physician, nurse, psychiatrist, social worker, physiotherapist, occupational therapist, and yoga teacher) who are supported by a dedicated group of nonprofessional volunteers. All volunteers do a basic course together and continue to meet on a regular basis. The service is able to care for between 10-18 patients at any one time, for an average of three months.

### **Hannah Eshed Hospice, Nof Hadar Hospital, Haifa**

The hospice was founded in 1992 as a unit within the private Nof Hadar Hospital. A multi-professional team provides palliative care in the 17-bed inpatient unit. The hospice has always worked closely with trained volunteers who provide support for patients and families (25). The unit is one of the four inpatient palliative care units formally recognized by the Israeli government.

### **French Hospital, St. Louis Mission, Jerusalem**

This “free” hospital is run by a French religious order, the Sisters of St. Joseph. The 44-bed hospital is dedicated to the care of all patients with “advanced disease,” regardless of their faith or belief (26). They have an 18-bed inpatient palliative care facility. Patients may be referred by physicians or oncologists from other hospitals (13).

### **Al-Taj for Health and Heritage Association**

This charitable association is being established as a volunteer-run home hospice service in north Israel. The service is operating with the founder, Kassim Baddarni, who is a registered nurse, able to undertake home visits to around 20 cancer patients. A needs assessment for the organization is completed. A multi-disciplinary team of two full-time and 10 part-time volunteer health professionals and lay support staff enrolled for an official start in January 2006 (27).

### **Additional hospital-based services**

The *Italian Hospital, Haifa* provides palliative care for patients at the end of life (28). The 95-bed hospital, founded in 1905 by Italian doctors and staffed by a religious order of nursing sisters, developed an oncology unit in the 1950s; this is now supervised by the *Rambam Hospital*, a large regional medical center in Haifa (29). The unit offers palliative care (including palliative radiotherapy with a treatment capacity of up to 500 patients a week) and psychosocial support (28).

A Reiki healer is currently working as a volunteer in the *Rambam Hospital* oncology unit, offering Reiki healing to all cancer patients at the unit who request it, at whatever stage in their illness (30).

### **Pediatric Support**

At the time of this report (2005) there are no government-recognized or formal specialist palliative care services available for children in Israel (31). There are, however, a number of informal and general services offering consultation, advice and psychosocial support for children at the end of life. Palliative consultation and support is offered by pediatric oncologists at:

Chaim Sheba Medical Center, Tel Aviv

Edmond and Lily Safra Children’s Hospital

The Marion and Elie Wiesel Children’s Pavilion (although specialist palliative care is no longer the

emphasis in this unit, support is provided for children at the end of life)

Rambam Medical Center, Haifa

Meyer Children's Hospital (This hospital, based at Rambam Medical Center, has no formal palliative care service; however, medical oncologists Dr. Sergey Postovsky and Professor Miriam Ben Haroush are dedicated to providing pediatric palliative care whenever needed.)

Negev Palliative Care Services (Ben-Gurion University of the Negev—Faculty of Health Sciences) offer pediatric palliative care consultation at the

Children's Hospital (Soroka Medical Center, Beer-sheba)

The home care multi-professional team at:

Jerusalem Home Hospital will care for children and young people at the end of life

Members of the Psycho-Oncology Society working at:

Schneider Children's Medical Center, Rabin Medical Center, Petah Tikva, Tel Aviv offer palliative support for children and also provides bereavement support for parents (32).

### Community Health Centers

There is a network of around 80 community centers that offer a home medical and nursing care service for patients with a range of sub-acute and chronic conditions, including those at the end of life (33). These community-based services vary in different locations; the extent and expertise of the palliative care offered depends on whether medical and or nursing staff have had specialist training (15). Within the available cancer services throughout Israel, there are around 500 oncology nurses with specialist oncology postgraduate training, which includes training in palliative care and symptom management. These nurses are working in hospital oncology units or community settings. Currently, around 30 oncology nurses have completed further training in palliative care and some are now working within hospices (hospital- or home-based) (34).

### Oncology Units

Several oncology units provide psychosocial support for patients. A particularly comprehensive service has been developed by psycho-oncologists at the Beilinson Unit,

part of the Davidoff Center, opened in 2005, at the Rabin Medical Center, Petah Tikva near Tel Aviv. This support is offered not only for inpatients at the end of life but also for patients attending the unit throughout treatment, regardless of outcome (32).

## REIMBURSEMENT AND FUNDING FOR SERVICES

Specialist palliative care services in Israel are provided in a number of different health care settings most of which rely on complex sources of funding (Table 6.2). Patients with cancer are entitled to free medication. Patients with other illnesses are entitled to medication, including opioids, at a discounted rate depending on their health plan insurer; usually this is a flat rate per prescription.

Palliative care services which are entirely charitable and relying on donations are able to offer all patients free care and consultation. There is one private service available to any patients able and willing to pay fees. Health plan insurers are also referred to as health maintenance organizations (HMOs) (35). Three services receive a combination of charitable funding and HMO funds. One service has made the transition from combined funding to HMO/Ministry of Health (MoH) funding only; HMO funds all include an annual per capita proportion of government MoH funds. Some palliative care services operate within one of the institutions owned and run by Clalit Health Services; the oldest and largest of the four nongovernmental health plans providing insurance, which provides services to 55% of the population. Where an HMO, such as Clalit Health Services (Kupat Holim Clalit) runs all or part of the service the patient can only receive free care for a certain number of services if they are signed up to that HMO insurance.

Charitable funding may include monies from national and international donors from institutional or private sources. Currently the largest and most generous national, institutional donor funding palliative care services is the Israeli Cancer Association. The Jewish Federation in the USA (specific donor branches include New York and Detroit) is a major international donor. Charitable funds support a range of activities in a service: funding a health professional post; providing financial support to run a service; funds for individual projects as part of establishing a service; new facilities within a service; research and development.

Although an institution within which the palliative care service is based also receives a percentage of MoH funds, the palliative care service does not itself receive any direct

Table 6.2 Funding sources for hospice and palliative care services in Israel

Organization or service	Institution (if applicable)
<b>HMO Health plan funded – all with Kupat Holim Clalit (includes annual per capita proportion of MoH funds)</b>	
Tel-Hashomer Hospice * Edmond and Lily Safra Children’s Hospital The Marion and Elie Wiesel Children’s Pavilion	Chaim Sheba Medical Centre
Cancer Pain and Palliative Medicine Service, Sha’are Zedek Medical Center	Sha’are Zedek Medical Centre
Negev Palliative Care Services ~ home hospice ~ hospital consultation service	Ben Gurion University of the Negev / Soroka Medical Centre
Jerusalem Home Hospital	
Schneider Children’s Medical Centre	Rabin Medical Centre
Meyer Children’s Hospital	Rambam Hospital, Haifa
<b>Combined HMO (all with Kupat Holim Clalit) + charitable – (international /national and or local donations)</b>	
Negev Palliative Care Services ~ desert mobile unit ~ Ma’agan House	Ben Gurion University of the Negev
Nancy Caroline Hospice of the Upper Galilee	
Milton and Lois Shiffman Home Hospice in the Valleys	
Ina and Jack Kay Hospice	Hadassah Mount Scopus Hospital
<b>Charitable – (international /national and or local donations)</b>	
Home Care Hospice of Kiryat Tivon	
St. Louis Mission, Jerusalem	Sisters of St. Joseph
Italian Hospital, Haifa	
<b>Private fee paying</b>	
Hannah Eshed Hospice	Nof Hadar Hospital, Haifa

\*Tel Hashomer Hospice inpatient unit has made a transition from combined charitable/HMO to HMO/MoH funding

government funds. The competitive nature of government versus HMO allocation can result in loss of funds for the service (36). Some elements of community-based services and half of all acute or rehabilitation hospitals are government funded, and patients can access free care if they have Israeli ID with paid up National Health Insurance (NHI) benefits. However, no government-funded NHI directly funds any specialist palliative care service. Hence, access to any degree of specialist palliative support within government-funded settings is entirely dependent on whether physicians or nurses in that unit or institution have received specialist training elsewhere (15).

Palliative care is not in what is known as the “basket of services” of the four national HMOs, who consequently are under no obligation to fund end-of-life care (13). HMO funding is subject to continual negotiation, i.e. year on year (or in some cases month on month) (37) and

accordingly the palliative care services funded through a HMO have been found to be financially precarious and subject to sudden loss of funds (38). In fact, some (though not all) services funded either entirely or in part through charitable, nongovernment organizations (NGOs) may have greater financial security if they are fortunate to have highly committed benefactors and regular donations (39).

## OPIOID AVAILABILITY AND CONSUMPTION

In Israel the commonest generic opioid in use is morphine sulphate used as oral tablets, as injectable solution, or in IV infusions and subcutaneous “pumps” (syringe drivers). There is widespread and increasing use of proprietary opioids such as fentanyl (Durogesic), oxycodone and

hydromorphone. Pethidine is used for palliation in some hospitals and nursing homes, but more physicians are now prescribing either generic or proprietary morphine salts (40). Some physicians find that patients and pharmacists are happier to be prescribed proprietary opioids as the names do not suggest an obvious association with morphine (16).

Other synthetic drugs with opioid properties, such as tramadol, are used extensively by some physicians in cases of moderate to severe pain, particularly as these analgesics are subject to fewer restrictions and can be used for people who are morphine intolerant. Non-opioid sedatives such as midazolam are widely used by specialist palliative care physicians (41).

The current law permits physicians to prescribe up to 10 days' supply of opioids per prescription which can be increased up to 30 days' supply if there is good justification. There is no upper limit set on opioid dosage per prescription. Dr. Nathan Cherny, Director, Cancer Pain and Palliative Medicine, Sha'are Zedek, describes the current legislative and access situation:

“We have excellent access to all analgesics and for patients with advanced cancer the analgesics are all free of charge and we don't have dosing limitations. The prescribing limitations; you can prescribe only one month at a time but that's not insurmountable and so there is excellent availability of drugs.” (13)

In spite of legislation permitting 30 days' supply, the preference is a maximum 10-day prescription, as Dr. Amitai Oberman, Medical Director, Home Hospice of the Valleys, explains:

“There is a possibility that if you write on the prescription that the patient is bed-bound, you can get it for 30 days. That's more tricky and the pharmacies sometimes don't like it, but if you give them a call it's fine, but otherwise you would have to fill it for 10 days.” (42)

Unless, however, prescribing physicians are specifically trained in palliative care or pain management, it is still the case that not all physicians have the necessary confidence or training when prescribing opioids. Amitai Oberman continues:

“You know, you have to learn how to write a prescription for opioids and people don't know how to write such a prescription, they make mistakes and some of the pharmacies are a bit hesitant when they see, like, colossal doses of fentanyl, but on the whole I think we're doing OK.”

There continues to be a need for improvements in prescribing practices for palliative pain relief and symptom control (43). Most commentators emphasize the importance of ensuring adequate and sustained education and training for physicians (and pharmacists) at all levels. Dr. Jim Shalom, Medical Director of the Nancy Caroline Hospice of the Upper Galilee (HUG) describes some issues in the current situation:

“One of the [notes] that [hospice founder] Nancy [Caroline] had on her refrigerator was that ‘Pain is a medical emergency.’ In other words we encounter problems with two types of physicians. We encounter problems with what I would—and I'm generalizing—with physicians who just back away from any involvement with cancer patients, including referring them to us. For a long time, and probably still in areas that are underserved, people just don't get treated properly: they don't get treated by the hospital and they don't get treated by the family physicians properly—although hopefully there are less and less of them. So that's one category. The other category is the sort of proud family physician; he knows his stuff and thinks that he can handle it, when today really palliative care is different than it was 15 years ago. It's far more complex, you know, the drug regimens are more complex and the orientation is far more sophisticated than it was before.” (44)

Aliza Yaffe, Head Nurse at the Israeli Cancer Association, echoes these concerns, particularly the ongoing need to teach the principles of pain management:

“The other day, one of the nurses came and said she went to see a patient in our regular surgical department. The doctor said that the patient that I was visiting, he's not in pain but he is very restless. So we have to decide, do you treat that restlessness or not? Everybody must treat restlessness. But [the doctor] said, ‘No, that's not pain so I'm not giving anything, bring the oxygen.’ You know, you have to teach all the time, all the time, all the time.” (34)

## PALLIATIVE CARE COVERAGE

There is relatively wide palliative care coverage in some major cities and well-populated regions of central and northern Israel (Table 6.3).

Despite the existing range of services, there is considerable concern about the shortfall in palliative care provision, particularly in remote, rural areas of the country, but also in large population centers, such as around the Tel Aviv region.

Although many people at the end of life may have access to supportive care from one of the 80 community health services throughout the country, only a small proportion (relative to needs of the population) have access to one of the 27 specialist home hospital-based or inpatient hospice services.

### Central Israel

In central Israel there are five specialist palliative care services for adults and four centers supporting children. Four of the five available services can only care for cancer patients:

four of these services are based in Jerusalem (with a combined city and district catchment population of 829,800) (45).

Tel Aviv (with a combined city and district catchment population of 1,177,300) has one specialist service for adults with cancer; three centers support children. Only an estimated 15-20% of the population has access to specialist services. Supportive care for adults is offered via hospital and community services.

### Southern Israel

There is one specialist service in the south that provides coverage in three cities and some of the surrounding desert region including:

Beersheba, the capital city of the Negev Desert, with a catchment population of about 180,000 people.

Rahat, a Bedouin city, providing for a population of around 32,000. A palliative care team cares for patients in the city and in the neighboring Jewish kibbutzim outside the city.

Qiryat Gat, a city 50 kms to the north of Beersheba with a population estimated at 50,000. A team cares for patients in the city and those living within a radius of around 20-30 minutes drive from the city.

The mobile palliative care unit provides coverage for the Bedouin people living in remote settlements up to 40-50 kms south of Beersheba in the desert region (15).

Table 6.3 Palliative care coverage in Israel (2005 estimate)

Service	Inpatient bed capacity	Home hospice capacity (maximum)	Day/outpatient/ hospital capacity (estimate)
Tel-Hashomer Hospice, Sheba Medical Centre	22	25	
Ina and Jack Kay Hospice, Hadassah, Mount Scopus	14		
Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center	22		1000
Hannah Eshed Hospice, Nof Hadar Hospital, Haifa	17		
Negev Palliative Care Services		75 (estimate)	450
Milton and Lois Shiffman Home Hospice in the Valleys		45	
Home Care Hospice of Kiryat Tivon		18	
Jerusalem Home Hospital		300	
Nancy Caroline Hospice of the Upper Galilee		35	
St. Louis Mission, Jerusalem	18		44
Italian Hospital, Haifa			95
<b>Total</b>	<b>93</b>	<b>498</b>	<b>1589</b>

### Northern Israel

There are three home care hospices in the north; one service provides coverage in Nazareth with a catchment population of 350,000 (22). In the Upper Galilee and northern Golan Heights areas another service based in the small town of Rosh Pina covers a catchment population in the region of 150,000 (37). In Kiryat Tivon one service provides coverage for the population of 14,000.<sup>46</sup> There are two hospital-based services in Haifa, the largest northern city (with a combined city and district catchment population 852,600) (47).

Palliative care in Israel is focused on patients with cancer. In 2004 a study of palliative care services in Israel conducted by Dr. Netta Bentur at the Myers-JDC Brookdale Institute, Jerusalem, estimated around 95% of all palliative care patients have cancer. Only 5% of patients with other illnesses have access to one of the four specialist palliative care services able to care for them. In 2004, only an estimated 2,000 cancer patients received specialist hospice care of the total new cases of 15,000 cancer patients that year, many of whom would benefit from these services (48).

### PALLIATIVE CARE WORKFORCE CAPACITY

The total palliative care workforce capacity (full- and part-time) in Israel estimated in 2005 is shown in Table 6.4.



**Illustration 6.1: Tel Hashomer Hospice, Tel Aviv, Israel**  
[photograph: Amanda Bingley, May 2005]

### Tel Hashomer Hospice

The hospice employs around 30 full- and part-time staff: medical director, inpatient hospice physician (who also coordinates research for the inpatient unit), 10 full-time nurses including head nurse and 10 part-time nurses, secretary, part-time staff including social worker, physiotherapist, and clinical psychologist. Other professionals are called in as needed including occupational therapists and a spiritual counselor. The home care staff includes one physician, three home care nurses, and a part-time social worker (9). The home care team can request a physiotherapist from the HMO for a patient if needed. The hospice also has support from about 22 volunteers (49,50).

### Ina and Jack Kay Hospice

The hospice employs around 29 full-time and part-time staff: hospice director, physician, 25 nurses (three nurses rotate duties between home care and inpatient unit), and two social workers. They can also call on external services for a psychologist and physiotherapist when needed (10).

### Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center, Jerusalem

The service employs around 32 full-time staff: five full-time physicians, including two oncologists, a physician fellow, a consultation psychiatrist, a clinical psychologist, a specialist palliative care nurse, a research and education coordinator (who is also a clinical pharmacologist), three multi-lingual social workers, a spiritual counselor, a palliative care nurse for the day care unit, seven oncology nurses; inpatient ward staffing is allocated an additional six nurses according to patient numbers, and four nursing aides. There are also regular placements for up to four medical internees, and for medical, nursing, and spiritual counseling students.

### Negev Palliative Care Services

The service employs a total of around 22 full- and part-time staff. The service also has placements for three or four physicians at any one time who are completing residencies in palliative medicine as part of their family medicine training. Around 12 full-time and part-time staff are based in Beersheba: head of division, medical director, four part-time physicians, one full-time and three part-time nurses, a full-time social worker and a part-time social worker who can be called upon from another facility. Two part-time physicians and two part-time nurses are based in Qiryat Gat. One part-time physician, one part-

Table 6.4 Estimated palliative care workforce capacity in Israel (2005)

Role in palliative care	Estimated workforce employed full- or part-time	Estimated workforce available on needs basis
Administrative staff / director		
Physician/medical director	69	
Nurses ~ of which specialist nurses	142 ~ 2	
Social worker	20	
Psychologist	4	1
Physiotherapist	4	1
Occupational therapist	3	1
Music / art / yoga	1 / 1 / 1	
Spiritual counsellor	2	3
Volunteers (trained)	60+	

time nurse and a part-time driver are based in Rahat. The mobile desert unit is allocated three part-time staff: a physician, a nurse and a driver. A social worker and a group of volunteers are based at Ma'agan House (15).

### Milton and Lois Shiffman Home Hospice in the Valleys

The hospice employs 31 part-time staff: hospice manager, six physicians including the medical director, 16 nurses, six social workers, and a team secretary. One of the social workers is also the volunteer coordinator managing around 20 volunteers at any one time (22).

### Jerusalem Home Hospital

The service employs around 50 staff including two consultant geriatricians, a consultant medical oncologist, 30 part-time physicians (paid on a fee per patient basis), seven full-time and five part-time senior nurses (including a specialist oncology nurse), 35 part-time nurses, speech therapist, occupational therapist, physiotherapist, social worker, and dietician. Volunteers offer additional support for patients and families (24).

### Nancy Caroline Hospice of the Upper Galilee (HUG)

The hospice employs 13 staff: medical director, three physicians, four nurses (one is a specialist palliative care nurse) a social worker, part-time music thanatologist, art therapist, secretary, and clinical psychologist. The hospice has support from a group of trained volunteers (37).

### Home Care Hospice of Kiryat Tivon, Northern Israel

The hospice is run by 12 paid and volunteer professionals and 20 trained lay volunteers. Professional staff include four on-call physicians plus an internist physician, head nurse, two oncology nurses, social worker, physiotherapist, occupational therapist and a yoga teacher (46).

Exact numbers of workforce are not available for other adult and pediatric hospital-based services, community or other non-specialist services. There are Israeli Cancer Association funded individual specialist nurses in some adult and pediatric oncology units.

## NATIONAL AND PROFESSIONAL ORGANIZATIONS

There are three national and professional organizations concerned either totally or in part with palliative care; for example, promoting awareness, organizing or advising on training programs, raising or providing funds for services; the *Israeli Association of Palliative Care (Tmicha)*; the *Israeli Cancer Association*; and the *Israel Palliative Medical Society*, which is affiliated with the Israel Medical Society.

### Israeli Association of Palliative Care (Tmicha)

Established as a voluntary (not for profit) association in 1993, the *Israeli Association of Palliative Care (Tmicha) (IAPC)* is an organization for all health professionals and trained volunteers actively involved in palliative care in Israel. IAPC membership includes leading figures in palliative care, who encourage professional and public education about the concepts of palliative care and pro-

mote the development of services. Membership, which is currently around 800, is open to all health professionals, volunteers and interested lay people that identify with its philosophy.

Initially chaired by Dr. Ilene Ora Cibulski, the IAPC produced a biannual Hebrew/English newsletter, *Support*, until her retirement in 2000 (51). Since 2001, the IAPC has been chaired by Mali Szlaifer, who is dedicated to continuing to develop training and networking for its members and for palliative care services around the country. IAPC has an elected Board of Directors that aims to represent all the professions involved in palliative care and from a range of different services. The work of IAPC includes:

Convening annual conferences, regular meetings and study days, seminars, and training programs for health professionals—including physicians, nurses, social workers—and also for trained volunteers, all of whom are actively working in the palliative care services (22)

Involving members in teaching on the professional palliative care programs in Israel

Promoting clinical and academic research by its members and the dissemination of findings within the association

Campaigning via conferences, publications and the media to have palliative care included in the NHI legislation; and to advocate for the rights of terminally ill patients with palliative care included in the NHI

Supporting local projects that are developing and expanding services throughout the public sector

Defining palliative care and developing standards of quality and adequate service provision

Collating data on existing services, with the aim of publishing a guide to services for use by health professionals and the public (52).

The association puts an emphasis on the importance of collaboration between health professionals from different disciplines with the aim of encouraging maximum support for patients and families. IAPC is a collective member of the European Association for Palliative Care (EAPC).

### Israel Cancer Association (ICA)

Established in 1952, as a not-for-profit nongovernment organization, the *Israel Cancer Association* is dedicated to the education and development of services for professionals working in the field of oncology and to promoting treatment, support and services for cancer patients and their families. The ICA has a long-term aim to “reduce the mortality and morbidity rates of cancer.” (53) Since 1983, with the opening of the first hospice (Tel Hashomer) which was funded collaboratively by the ICA, MoH and HMO Kupat Holim Clalit, the association has also addressed the need to support and fund the development of palliative care in Israel. The association is now the largest national source of nongovernment funding of palliative care services.

The ICA works both independently and in collaboration with HMOs and the MoH, to fund service provision, work placements and posts (physicians and nurses) education, training and research. Since the early 1980s Aliza Yaffe, ICA Head Nurse has, with other professional colleagues, promoted the concept and development of specialist oncology nurses, which now includes offering additional palliative care training, by providing grants for training and posts. The concept of the specialist oncology nurse was initiated in part by recognizing and responding to the needs of health services and in part by those health services realizing the benefits of having specialist nurses, as Aliza Yaffe explains:

“The manager of the health service in that specific section came each year to Israel Cancer Society and said we would like to have an oncology community nurse. I did lots of lobbying for a while, and that nurse, her job would be this and that as needed [for example], specifically in Arab communities she will take care of, let’s say, more elderly people. The Cancer Society (ICA) gives a grant of half-time for a registered oncology nurse for three to five years. Afterwards, they [the community health service] will absorb that job.” (34)

Those oncology nurses working in community health centers who have completed palliative care training can now offer nursing care at the end of life, alongside their work with cancer patients during and after treatment. The ICA manages a website which provides information about promotion of cancer prevention, raising public awareness for example, about smoking. ICA also runs media campaigns, produces multi-lingual leaflets and publications about cancer prevention, early detection and available cancer-related services. The association has a telephone helpline providing public information (53).

### Israel Palliative Medical Society (IPMS)

This organization, established in 1996, is a branch of the *Israel Medical Association*, and is chaired by hospice physician Michaela Bercovitch. Election to the board of directors is restricted to physicians but general membership is open to other health professionals including nurses, physiotherapists and social workers. The aim of the IPMS is to represent physicians and other health professionals involved in palliative medicine and to promote palliative medical services, education and research: there are plans to develop a training fellowship (9). The IPMS, together with the other national organizations, is actively working towards the recognition of palliative medicine as a specialty by the Ministry of Health and the development of national clinical guidelines in palliative care. The society, with its own publication, the *Journal for Palliative Medicine*, encourages meetings, seminars and participation in national and international conferences, and links with national and international palliative medicine organizations. The IPMS is a collective member of the European Association for Palliative Care (EAPC) (54).

There are two international organizations: *European Association for Palliative Care (EAPC)* and the *European Society Medical Oncology (ESMO)* both of whom support and provide educational links for palliative care professionals in Israel, involving professionals in conferences, networking, and dissemination of publications (55).

### EDUCATION AND TRAINING

Education and training for all health professionals is regarded as key to the development of palliative care services in Israel, and has been an important aspect of service development from the early 1980s, with the opening of the first hospice. Since the late 1990s there has been an increase in organizing and developing training with more courses available (42). Although palliative medicine is still not recognized as a specialty in the health care service, it is part of all general nurse training and also part of postgraduate oncology nurse training. Some medical schools include short units for fifth year medical students. There are currently also training opportunities in Israel for physicians at postgraduate level with a two-year diploma course at Tel Aviv University for physicians coordinated by Alexander Waller, Medical Director and Michaela Bercovitch, hospice physician, Tel Hashomer Hospice (Table 6.5).

Nathan Cherny, Director of the Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center, Jerusalem, explains the current situation:

“Palliative care is part of core training for nurses and it is an integral part of the training for oncology nurses. Palliative care training for oncologists is weak and relatively ad hoc, despite the fact that at least on paper they have adopted the curricular guidelines of the European Society of Medical Oncology (ESMO) which are fairly stringent guidelines as to what has to be incorporated in training, it's between the policy and practice that there continues to be a gulf. Outside of the oncology framework palliative care is very under-developed; when the AIDS crisis was at its peak there was an inpatient hospice but the whole picture has changed. But for people with degenerative neurological diseases or whatever they fall into the rubric of whatever of the home care services but in a very ad hoc manner and not necessarily with a lot of skilled care. In terms of physician training there is a diploma program in palliative care that has been running for a number of years and I think has put through probably close to about 90 or 100 graduates. It's a two-year part-time program through Tel Aviv University, which has been primarily coordinated by Alex [Alexander Waller, Medical Director, Tel Hashomer Hospice] and has been a very successful program, and people come to do that from a broad variety of disciplines and from very diverse parts of the country. The specialty accreditation is all coordinated through the Israel Medical Association. At present they are resistant to the development of palliative medicine as a subspecialty but there are moves afoot to have a fellowship recognized. In the presentation that was made the recommendations have gone to the Ministry of Health, this issue is being addressed but these decisions are not in the hands of the ministry alone.” (13)

In addition to formal education courses there are a variety of training programs for health professionals (physicians, nurses, social workers, psycho-oncologists, spiritual counselors and creative therapists) that are organized by individual palliative care services and also as part of the work of national associations (see IAPC, ICA, IPMS). These programs include study days, seminars, conferences, Continuing Medical Education (CME) courses and specialist training units.

*Israel Cancer Association (ICA)* has a strong commitment to professional and public education. Since 1978, Head Nurse Aliza Yaffe and her colleagues at ICA have pioneered a specialist community oncology nurse training, which includes stoma care, breast care and palliative care. One of the current goals is to create a palliative care nursing specialty. ICA funds short specialist programs, for example training radiographers in mammography. Regular public education programs are organized to raise awareness about cancer, early detection treatment, and support (34). ICA also funds research into cancer, in-

cluding initiating and evaluating new developments in medical and nursing services.

*Israeli Association of Palliative Care (IAPC)*, in collaboration with the *Israel Cancer Association* and *Ben Gurion University of the Negev*, is currently organizing short “train the trainer” courses in different centers around Israel. Three courses ran in 2004, and five in 2005. These are run as a 40-hour course with the hours divided equally between psychosocial issues, physiology, symptom control and pharmacology. Nurses can get CME (Continuing Medical Education) points for attending. IAPC board member Dr. Amitai Oberman describes the future direction for palliative care education:

“I believe that geriatric and oncology postgraduate nurses should know something about [palliative care]. On the whole the feeling is that positive things are happening, and the last two years have been very fulfilling and we see change, and there’s money and there’s more people, and

people are coming to the conferences, which have been very, very successful. We are able to attract more professionals and more public figures and health professionals, key leaders in medicine. Tons of work to do, especially within the hospital system, but the fact is that we have this committee which also Pesach [Professor Pesach Shvartzman] headed, from the Health Ministry, is a major change. It will take time ’til it will be implemented and there will be money and funding for palliative care, but it’s a change, it’s a move.” (42)

Many services also train volunteers as part of their ongoing work. There are other specialist programs including spiritual counseling, and international opportunities, such as fellowships and Master’s courses.

At Ben-Gurion University of the Negev there is a program of palliative care residencies for trainee family medicine doctors run through the Negev Palliative Care Service. Through the university’s Faculty of Health Sciences the

Table 6.5 Palliative care education and training available in Israel - 2005

Core education		National specialist education and training		International education/ links
Physicians	Nurses	Diploma/MSc/CME/Specialist courses	Short units/ seminars	Fellowships/diplomas/ Master’s/short courses/ etc.
Short units of palliative medicine accessible in some medical schools for 5 <sup>th</sup> yr medical students (full inclusion as part of core curricula in all medical schools is under development).	All general nursing courses include a unit of palliative care nursing. Several inpatient hospice units offer placements for student nurses for training in palliative care.	Physicians: postgraduate diploma (2 yr/400 hours—includes 48 hrs clinical experience).  Nurses – postgraduate Oncology Nursing qualification includes training in palliative care and symptom management. Further training available, as below.  Physicians and nurses working in palliative care services can take available short courses for CME credits.  “Train the trainers” short courses (40 hours) run in different venues around the country – these are mostly for physicians and nurses.  Specialist courses (which include placements for students within existing specialist services) are available for health care professionals/trainees including psycho-oncologists, psychologists, social workers (e.g. the Master’s course, with placements at Ina and Jack Kay Hadassah), spiritual counsellors. Many hospice teams train their own hospice volunteers.	Regular short courses run from the IAPC, ICA and from hospice services. These courses are designed for physicians, nurses, social workers, allied health care professionals and trained volunteers.	Physicians and nurses can apply for Master’s level degree courses, diplomas and fellowships in other countries, e.g. USA and UK.  Short seminars and courses are accessible for health care professionals working in palliative care via international organizations, such as ESMO, ASCO, EAPC, MECC etc.  Specialist training for creative therapies in palliative care, e.g. art therapy and music thanatology, are accessible in the US and UK.

palliative care service runs a variety of postgraduate and undergraduate courses. These include short training units for medical and nursing students as part of their professional development; postgraduate courses, seminars, and specialist training for oncology nurses. Medical Director Dr. Yoram Singer explains current developments in palliative medicine education and research, including more details about the collaborative “train the trainer” courses:

“We are more and more involved in education, to get [palliative medicine] into [the] undergraduate curricula. At the moment we are more involved in Continuing Medical Education (CME) courses for medical professionals—nurses and doctors mostly—and, because of the success of the mobile unit, we got extra funding for this from the New York Federation. [NYF funded the Negev desert mobile unit.] They are enthusiastic at how things work. We had a six-day get-together for a “train the trainer” course, and there we [developed] the curriculum. Now we’re in the middle of running [courses], ’til the end of June we will run three national courses on palliative care (40 hours each). It’s very interesting; the enrollment is from social workers, nurses and doctors: multi/interdisciplinary experience. Now we have requests from many other places and we’re slowly building it up. And, of course, [we have] the family medicine medical students. We do a little bit of research, more audit kind of research at this stage.” (15,56)

*Middle East Cancer Consortium (MECC)* as part of its ongoing educational and research work organizes regular seminars in cancer registry and in oncology (57). Since 2004 MECC has also started to address the need for information and education in palliative care for all health professionals working in the field. The consortium has funded members to attend courses with the American Society of Clinical Oncology (ASCO) and has set up a collaborative “training the trainers” palliative care course between Calvary Hospital, Virginia, USA and the oncology unit in the Italian Hospital, Haifa. In February 2004 and November 2005 palliative care seminars were run for health professionals from MECC member countries (28).

With the growth in education and training in Israel, there have also been more opportunities for research in the field. There is currently a well-established clinical and academic research base in palliative care, with a strong record of extensive national and international publications and dissemination at international conferences. Key research in palliative care is undertaken by clinical and academic researchers from all disciplines involved in palliative care provision, many in collaboration with major

universities in the country (58). Major areas of research include pain and symptom management (59–62), pain assessment and needs (63,64), and cultural aspects of palliative care (65,66). Palliative care research publications are also internationally disseminated from nursing and related clinical health professionals including social work, psychologists (67), therapists, and academic health researchers.

## ETHICAL ISSUES

Several ethical dilemmas have been identified in palliative care in Israel. These include disclosure of prognosis, the impact of genetic testing on discussions of prognosis with patients, decisions about stopping treatment when a patient is at the end of life, children and bereavement, the new law of the dying patient, and inequalities and difficulties concerning shared responsibilities when managing service provision. There is also a continuing problem of opioid “phobia,” which affects access to pain relief and symptom control.

In Israel patients have the right to full disclosure of prognosis from their physicians. However, there are many problems that continue to arise with families requesting that the doctor not tell the patient, as Professor Shvartzman explains:

“The main issue that arises all the time is getting into the house and people telling you, family members telling you, ‘Psst, don’t tell anything to the patient.’ I think that’s the most problem, ‘Don’t tell him anything at all, if he finds out he’ll commit suicide.’ And it’s a very complicated issue because, first of all, we are visitors, so you go to their house; you have to be polite, you cannot say, ‘Hey, I’ll tell you what I’ll tell you.’ But still you have to do what you have to do, so I think that’s the most common issue....What happens is the son says ‘Don’t tell Dad that he has cancer, or he’ll be upset.’ Dad says to his son, ‘Joseph, go in the kitchen, make a cup of tea for me, a cup of coffee for the doctor, get the cake from the larder and do something else...’ and as the son’s going out, ‘Don’t tell Joseph that I have cancer, he’ll be devastated if he finds out.’ That’s what usually happens.” (16)

This situation is changing as there is more awareness through the media. Although as Amitai Oberman explains, physicians still withhold information:

“They tend not to tell, on the whole. Nathan always says the physician is the first liar, which is true. Usually, in many cases it is up to us, or the oncologist will say, ‘You don’t have to come any more. If you want you can come again.’ In many situations we don’t directly speak to the

patients, but it varies from culture to culture and sometimes theoretically you would think that you would [discuss this less] with more orthodox people, but we've found that we will discuss death with the rabbis and imams and sheikhs. It varies: it's not based on a socioeconomic or education level or anything like that, it's very personal, I think. But, compared to America where I trained, we're still more paternalistic in Israel, but the system is changing *fairly* rapidly and people are getting orders to tell patients and getting, 'if you don't tell patients, you may be liable, they can sue you.' But still, there are problems, there are problems." (42)

Shlomith Perry, who has specialized in research on the impact of genetic testing for women with breast cancer, is very aware of the ethical dilemma this poses for families of people who may have the test and then have to be told about a poor prognosis:

"[I feel that] people should learn how to deal with this issue, all the genetic issues, all the medical genetics which become very important, to change the attitude to who is ill and who is not ill. Is a carrier ill or not ill, because few of them have preventive mastectomies? How do you divide the division from illness and health? So I think that the issue of the family is very important in this, in the genetics because DNA is a family affair, and also at the end. So I think that in the medical continuum, there are a few areas where the family becomes very important: palliative care, genetics, donating [organs]."

Shlomith Perry notes other ethical issues she has identified, around decisions by physicians and patients about whether to continue (or begin) treatment or when to stop treatment:

"It starts from the beginning, and here it will be more important. Palliative care will be well-established here, and part of the thinking in palliative care will be the influence on all the care of the patient. In Israel we don't know when to stop [treatment]; the patient wants more and more drugs and doesn't know when to stop. I think it's a problem in Israel, a society's not well educated to decide when to stop; they need all the time to continue. They all need education, how to be more conscious, more aware of the decision, not to take more chemotherapy and more chemotherapy because you can stop chemotherapy. I think we don't know it. I think that in Israel we take the most and expensive drugs, because then people want more and more and more. This environment is that you must treat, you know, I think this is a Jewish cultural [thing] that you have to save people." (32)

Ruth Gassner at Hadassah agrees that this is a problem at the very last stages of life and describes how they deal with the issue in the hospice:

"The way forward is to talk with patient and family. I think they look at every case from a start at the zero point all over again. We haven't made decisions like: we don't give blood, or we don't give feeding tubes, or we don't do this. Every case is an individual case and we start depending on who the patient is, what the family wants. We are very open, talking to them."<sup>10</sup>

There are many ethical concerns about how to support children in bereavement prior to their relative's death. Social Worker Malka Yehezkel explains:

"Sometimes I feel when there are small children, that we won't let them come and visit parents or grandfather or grandmother; the patient doesn't want the visit, so what do we do? Usually, of course, first I try to explain and to work with the patient and to explain how important it is and that we can find a situation that will be OK for him, also not too difficult, not to let him feel he has to be nice and...even if he is sleeping just to let this child come and do his separation. ...I am so sure how important it is to help these children because I know how families try to protect them and try to avoid from them pain, so before death comes they try not to talk about, and I really do a lot of work with the family to help them understand how important it is to remember the children, to help them understand what's happening." (10)

There is an active debate in Israel about palliative care, euthanasia and assisted suicide, which, in 2005, culminated in the passing of a new law of the dying patient (68,69). Professor Abraham Steinberg, who chaired the committee on this debate, explains the kinds of ethical dilemmas they have attempted to address by passing a law that will attend to the needs of the majority of patients:

"I feel that it won't be fair not to provide the best palliative care to those who are suffering, who want to die, but if we provide them with palliative care they may still want to live, or at least have some reason to continue to live. And therefore we included as part of the law, which I understand there are very few countries, if any, that the law provides for the government to be responsible to give palliative care. Which means that the law says that every dying patient, obviously we can extend it to the non-dying, but the law talks about the dying, so we talk about the dying, every dying patient should get the best palliative care according to the standard at that time..."

“It should include finding for the accessories, for medications, for anything that palliative care demands, which nowadays is not available on a governmental level. And also we suggest that, not in the law but it comes out from this paragraph, that palliative care should be recognized as a field of medicine in the way that it should be studied, it should be recognized as a sub-specialty, there should be experts in the field - in other words it should be part of medicine like any other part of medicine, which I think is something new from a legal point of view, certainly in Israel but I think worldwide as well.

“On a philosophical level there might be differences on how we interpret palliative care: does it include always food and fluid and only no resuscitation, or does it include medication, routine medic-... I mean they are debates that are ongoing. So the standards of palliative care obviously will be presented by the experts and then there may be some variations on what is acceptable or not. Now whether it should be an acute care facility or in a hospice or in a home hospice or whatever, I mean, these are things that have to be worked out, I assume on individual levels, I mean, that has not to be decided on the *legal*, on a *law* level. Because I think that certainly the hospices know how to work with such patients, that’s their job, but the problem I think is in acute care facilities where patients of this kind are admitted, they’re being treated like anyone else, no one knows how to take care of the aspect of suffering of pain, and that’s where she should put more emphasis. Now whether to move them out or not is a very individual decision, but as long as they are here or in an old age home or even at home, they should get the best palliative care—that’s the concept. ... I know some people say that part of palliation is hastening death because he is suffering and, let’s say the Dutch, their view of palliative care is active euthanasia, it’s a way of palliative care—that obviously is unacceptable from a Jewish point of view, I think from a true palliative care perspective as well. But if it involves medication and support and family and the social and psychological, that is *very* positively viewed even if medication occasionally may hasten death; that is taken into account.

“In fact from a Jewish point of view pain and suffering is viewed as any other illness—let’s say someone has a brain tumor, what do you do for him? You take him to the operating room, you operate on him, and a few die on the table, so it doesn’t mean that you don’t operate because somebody died. So the same here, if you, if you equate pain to a brain tumor, the same way that there you give a treatment which is called operation and some die, you give a treatment which is called morphine or whatever and some die, so that really does not take away from the legitimacy, unless you purposely give such amounts that

will kill because you think that this is the way to help the patient, that is not a help from the Jewish point of view... If the patient *wants* to live, to continue living, even though from a medical point of view it doesn’t make sense, it’s futile—whatever futile means—you must provide him whatever needed for him to continue living, including palliative care. Now if the patient *doesn’t* want to continue to live, then it depends what he wants. If he just wants to withhold treatment that is fine; if he wants to withdraw treatment it’s also fine as long as the withdrawal is not causing instant death. So for instance if he’s on dialysis treatment and he got ten rounds and now he doesn’t want any more, so you don’t give the next one because it’ll take days before he’ll die because of his decision, so that’s a withholding process from the law.” (70)

The ethics that Professor Steinberg is working to resolve are closely allied to the inequalities of access to adequate and appropriate service provision. Palliative care consultant Dr. Ora Rosengarten discusses some aspects of this dilemma, which she and other colleagues face in home hospice care:

“First there’s always the problem of keeping the patient at home or not. One of the problems encountered is the question of whether to go on with the home hospitalization or not because, if the family and the patient is able to manage with all this, sometimes we do have the feeling that—this is not a majority—but sometimes we have patients who call other doctors who are involved in the treatment. In that case we have a real medical problem in managing and taking the responsibility for the treatment.

“We do have a problem sometimes when a patient is alone, he doesn’t have a family to support him, and the dilemma is whether to get in there and give him what we can, but we know that it’s not optimal because there’s nobody there to take the responsibility. Or [can we] leave him like this, because if you’re not there then nothing will be done? But if you are there you know you cannot do your job properly.” (24)

In spite of the increase in education and training, several palliative care specialists noted that opioid phobia and fear of sedation continue to be problems, both among health professionals and the public (71). Amitai Oberman and Jim Shalom in the north of Israel note that they still encounter physicians who are afraid to prescribe opioids. Amitai Oberman describes the practice of pharmacists who still put “poison” on an opioid prescription:

“I give a couple of lectures to pharmacists. It’s fascinating to talk to them because they have their own perspec-

tive, and stories. I can give them a call and say, ‘Look... please help us with this,’ and it’s usually fine. They’ve got their own laws and rules; they’re not allowed to be flexible—you can’t give this, and this has to be written down—and still when a patient gets a script of MCR, they put on the back sometimes a notice saying ‘poison’ on it. We’re working on them to try and convince them it’s not really clever to put ‘poison.’ But there’s still this thing about narcotics in Israel. But it is changing. Some of the old pharmacists keep putting, just out of habit, I think, ‘poison’ and during my talks, I have these slides showing them the obstacles to the perception of opioids and then I show them, and I say to them, ‘Who wants to take a drug which is poisonous?’” (42)

At Hadassah, Director Ruth Gassner and Social Worker Malka Yehezkel discuss the difficulties they find where patients ask for sedation, although the family may be afraid to see their relative sedated:

“That’s a dilemma that we have: the whole issue of sedating, when the patient is awake and asks us to sedate him and it comes from the patient.... When we deal with the dilemma, first we have to feel we know what we feel and what we think we are ready to start to do, and then we come to the family, because we don’t want to let them feel the responsibility is [just theirs] or the patients—we want to help, we want to be there really as helpers.” (10)

## HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

### Narrative history of palliative care

There has been a long history of hospice care in this region dating back to the Middle Ages with the Christian and Jewish tradition of hospices along the crusader and pilgrims’ paths providing care for the needy, sick and dying. One or two of these ancient institutions are still remembered in old names and buildings in Jerusalem (8). In the late 1970s a group of concerned nurses, led by Aliza Yaffe and her other colleagues based at the Israel Cancer Association (ICA), started to develop postgraduate specialist oncology nurse training, which was established in 1978 and included a component of palliative care and symptom management. As more nurses took up specialist nurse training there were greater opportunities for patients at the end of life to be cared for at home by specialist nurses, first as part of the family physician system and later as part of community health teams, where currently over 500 trained oncology nurses with palliative care skills continue to play a vital role in providing care at the end of life. Aliza Yaffe, head nurse at ICA, describes

the first ICA initiative to develop the community-based palliative care nursing service:

“It started in 1978, more or less at that time a few nurses of the American Oncology Nursing Society came here and presented a seminar on pain management. It was a good place to start thinking about some other things, not only the care of the patients in the hospital, but also to see what you can do to take care of persons in the community. And after we were finished that course—it was not a very long one, 80 hours that first postgraduate education—I came to the Manager and I said, ‘I think that we need to develop oncology nursing services in the community. The patient is staying in the hospital for a short time, and when he goes home then somebody has to go on taking care of him.’ The hospital experience is very short, and most of the time he will spend at his own home. It started with two nurses in Tel Aviv and Ramat Gan; their job was to get information from the hospital about who was going to be discharged and go and visit him at home and make an assessment of his needs, and try to take care of those needs. The theoretical model said that we are going to do that from prevention, early detection ’til bereavement, but it very soon became obvious that that couldn’t be done, because the patient was suffering a lot of symptoms, mostly pain. The nurses were working half-time; [they] had to go and see what the patients needed and to learn the needs of the nurses that are taking care of him. So it was a lot and then we said, well we will postpone the prevention, early detection for a little later, and we will try and do as good as possible symptom management. Very few [nurses] had access to a physician that would come with her to see the patient and help him. There were community nurses but they had no specific cancer nursing education: no palliative care, no cancer nursing. They came and they were very nice and they were very good at the heart but not so good at the other things.” (34)

By the early 1980s, this concern by the ICA to develop the skills and knowledge of nurses in end-of-life care for patients at home, and the needs of patients to have access to skilled care, facilitated the emergence of the modern hospice movement in Israel, which has overseen the development of freestanding hospice units and specialist home care services throughout the country (Table 6.6).

Since the 1990s, in spite of ongoing financial and political challenges, significant and steady development has continued in hospice and palliative care services, policy, professional education and public awareness.

The current situation from the perspective of positive and negative aspects of palliative care service development

is summarized by Nathan Cherny, Oncologist and Director of the Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center, Jerusalem:

“The things that are strong are now our very wide network of palliative care home care services, which are being provided in multiple different frameworks, many of them by the HMOs who are the payers, which go under different titles of home admission and oncology home admission or sometimes home hospice care. There are also several free-standing hospice services which don't belong to any HMO but which the various HMOs can buy services from.

“And there are different patterns of service delivery in different parts of the country. Most of the country, and this is talking about Israel as distinct from Palestinian territory has an increasing availability of some sort of home care. The quality of care is various and the training of manpower is very variable, and if one can make a generalization, the nursing element of the teams generally have some modicum of training in palliative care. The physician part of the team is very variable; from people who have got diplomas in advanced training in palliative care to people who really have no training, but who hopefully have some degree of supervision.

“I think that the last 10 years has seen a dramatic change in terms of the awareness of analgesics and the number of people involved in this endeavor is very large. Just at a local meeting of palliative care they get somewhere between 400 and 600 people. For a little country that's a very impressive number, it would be an impressive number in a big country. That's the positive side.

“The negatives; the downside is that the level of funding is very small and thus the amount of service you can obviously bring into people's houses is very limited. With very sick people, where you're going to be dependent largely upon family caregivers with really a relatively small amount of professional support, there are limitations as to how successful home care can be and how far it can go. The number of services available outside of the home: there are a small number of freestanding hospices, and to date there is only one inpatient palliative care unit in a general hospital which is the unit here. Overwhelmingly the rest of the hospitals in the country not only don't have dedicated palliative care beds but the palliative care services within the hospitals are generally limited to maybe a part-time nurse. There is no widespread recognition that this is an important service to bring in to hospitals. A commission was called by the Ministry of Health to get advice about improving palliative care services and a palliative working paper

has been presented to them, and one of the things that's been emphasized in that is the importance of developing palliative care inside general hospitals. Certainly given that most of the cancer services are in general hospitals we need to make sure that these are amply supported with adequate manpower.” (13)

Aliza Yaffe details more of the current challenges:

“When we look at the little map of Israel, if you will look at the whole area, we have so many different services and our problem is how people communicate with each other. If we do not have an inpatient hospice in Beersheba then we *need* one because not everybody can take care of a person in his own home all the time. You need a possibility, even for respite, even for a few days; let the family rest a little bit, to have a place where the patient knows the people that will be taking care of him and...and even if they want to open one more door and they're going to build something in his home to make it more comfortable. That's one of the things that I am sorry that is happening, that we are not really linked. The problem of inpatient hospices is that patients are not referred, not because they don't need to be, but because the health care system is reluctant to pay the price that the hospital management is taking for the service. That's very complicated and we should do more.

“The new service that we have developed is in the hospital palliative care, it should be a team but it's really [often just] a hospital palliative care nurse. This is something that we started about five years ago. One of the nurses, the head nurse of the hospice, developed it in Haifa in Meyer Hospital. The nurse is giving the service to the oncology department and patients that are suffering the symptoms are getting the treatment. She makes a whole assessment, and refers to the specific physician. Dr. Waller is doing that in Tel Hashomer; he goes to the oncology department once a week and has a clinic there. The nurse [refers] the patients that need his expertise, especially if they have a number of symptoms. Usually they are referred to their oncology nurse in the community if they are not [already an] inpatient. But if they are in the hospital then the staff are given [information] about what to continue, what to stop, and how to change treatment.” (34)

Individual service development since the opening of the first freestanding hospice in Israel is described below:

### Tel Hashomer Hospice

In 1982 Dr. Marian Rabinovitch, who was chair of geriatrics at Chaim Sheba Medical Center in Tel Aviv, and other colleagues in the Israel Cancer Association, decided

Table 6.6 Chronology of the establishment of palliative care services in Israel

Year services established	Organization	Type of Service Provision
Pre-1970s	Charitable religious hospitals; French Hospital, St. Louis Mission, Jerusalem and the Italian Hospital, Haifa	These charitable institutions have a history, throughout the 20 <sup>th</sup> century, of care for the dying. The Italian Hospital had specifically cared for dying cancer patients since the 1950s. Since the 1980s specialist palliative care units were developed within both these hospitals as the modern hospice movement evolved in Israel.
1970 - 1980	Israel Cancer Association (ICA)	Recognition and awareness of palliative care needs led to the start of opportunities for initiating palliative care training within a new specialist branch of oncology nursing that was developed from 1978 onwards. This led to the first community home care service run by nurses trained and funded by ICA in Tel Aviv.
1983	Israel Cancer Association at the Tel Hashomer Hospice, Chaim Sheba Medical Centre, Tel Aviv	First inpatient hospice for adult cancer patients.
1984	Home Hospice of Kiryat Tivon	First home care hospice service for adult cancer patients run by volunteers.
1986	Ina and Jack Kay Hospice, Hadassah Mt. Scopus, Jerusalem	Inpatient hospice unit for adult cancer patients.
1989	Tel Hashomer, Chaim Sheba Medical Centre, Tel Aviv	Home care service for adult cancer patients within 25 mile radius of Tel Hashomer Hospice.
	Ina and Jack Kay Hospice, Hadassah Mt. Scopus, Jerusalem	Home care service for adult cancer patients.
1991	Jerusalem Home Hospital	Home care service to include palliative care for adults and children with all kinds of illnesses.
	Negev Palliative Care Services, Beersheva	Home care service and hospital consultation for adult cancer patients.
1992	Hannah Eshed Hospice, Nof Hadar Hospital, Haifa	Inpatient private (fee paying) hospice unit for adult cancer patients.
1994	Hospice of the Upper Galilee (HUG) (now the Nancy Caroline Hospice)	Home care service primarily for adult cancer patients - children also cared for if requested.
	Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Centre, Jerusalem	Hospital-based day care, outpatient and inpatient consultation, now includes inpatient palliative care unit for adult cancer patients.
	Negev Palliative Care Services, Beersheva	Extended home care service for adult cancer patients to cover wide geographic area managed from a single base.
1999	Milton and Lois Shiffman Home Hospice in the Valleys	Home care hospice for adult cancer patients.
	Negev Palliative Care Services, Beersheva	Pediatric inpatient hospital consultation developed.
2004	Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Centre, Jerusalem	Spiritual counselling service developed.
	Negev Palliative Care Services, Beersheva	Mobile desert home care unit for adult cancer patients in remote geographic areas established.
2005	Ina and Jack Kay Hospice, Hadassah Mt. Scopus, Jerusalem	Counselling service provided by hospice team for hospice patients transferred to hospital.

to address the end of life needs of their patients. Dr. Rabinovitch explored hospice care in other countries, first in Germany and then England, where he visited St. Christopher's Hospice and was inspired by the work and teaching of Dr. Cicely Saunders. Returning to Israel he set up a multi-professional team with the support of Head Nurse Dvora Goren, and in 1983 they opened the first freestanding inpatient 25-bed hospice, Tel Hashomer, in the grounds of Chaim Sheba Medical Center. The care provided was based on the British hospice model pioneered by Dr. Cicely Saunders.

At Tel Hashomer, Dr. Rabinovitch was joined by other physicians, most of whom worked on placements from the Geriatric Department at Chaim Sheba. Physician Alexander Waller, who became Medical Director in 1989, took on Dr. Rabinowitz's work and with other colleagues developed the multi-professional team (physicians, nurses, physiotherapist, social workers, and clinical psychologist). The team was joined in 1991 by hospice physician Michaela Bercovitch; since 1998 she has taken on the post of Research and Information Coordinator (72). Tel Hashomer pioneered the hospice movement and was influential in supporting the development of other services, coordinating the establishment of professional training and education, and encouraging research. In 1989 the hospice set up a home care service for patients living within a 25-mile radius of Tel Hashomer. This service is now well-established and the nursing team can care for up to 25 patients at any one time (73).

### Home Hospice of Kiryat Tivon

In 1984, the following year after Tel Hashomer opened, a small home hospice was established in the little town of Kiryat Tivon in northern Israel. As the founder, sociologist and gerontologist Dr. Ilene Ora Cibulski, explains:

"I had the privilege of joining a wonderful group of people who were the first group who tried to create palliative home care, at the same time in Tel Hashomer, I heard Dr. Rabinovitch who was a geriatrician, he was actually the first [doctor in palliative care], talking about doing [palliative care] in a hospital setting. I said ninety per cent of the people, are ninety per cent of the time at home, the future solutions have to be in the community, and I had the privilege of having a physician, Dr. Miriam Boaz, who was the head of the outpatient clinic at Afula Hospital, and Professor Schaeffer Scharf who was the head of the rheumatology clinic in Haifa, Ramban Hospital, and Ruth Givon who became our head nurse, she was a public health nurse and she had developed community programs for infants who came out of the Holocaust. All of us together felt that we had to do something about what was happen-

ing...and we began immediately as an interdisciplinary team. ...For example, Professor Scharf, he would go to visit a patient, he would let the local physician know, this was a physician who never visited a patient, especially when [the patient] became homebound, and [physicians] never went to visit. The only people who did home visits at the time were nurses, physicians just didn't do it. ... We started a training course, and within a year we had about twelve volunteers, plus another twelve who were professionals and they were wonderful." (46)

### Ina and Jack Kay Hospice, Hadassah, Mt. Scopus, Jerusalem

In 1986, the second inpatient hospice in Israel based at Hadassah, Mt. Scopus, supported by a combination of funds from independent benefactors and the HMO, was opened by physician Dr. Reuvan Fink, Social Worker Roni Gertel, and Pediatric Oncology Nurse Ruth Gassner, who describes the early years:

"The hospice was opened in '86. I came one year before to think what we need, what we want, how to develop, how to start...the only place that we knew in Israel was Tel Hashomer, they opened in '83, so we went to Tel Hashomer, we visited to get some ideas. And in '86 we started the hospice with only one patient at the beginning. Before that I was in pediatrics, a head nurse in a pediatric department.

In '85 they decided to open, there was a big donation from the States coming from a Jewish family that donated a lot of funds and this went to reopen the renovation because the house was deserted [since the previous occupant, the Hadassah hospital director, had been killed during military action in 1967]. I started to recruit some staff, and I did it on my own intuition. I didn't know what I wanted; I just knew that I wanted good people. Most of the staff working here in the hospice [now] are people that started with me in '86."

In 1989, supported by donations from independent benefactors (the Crown Fund) the hospice opened a home care service, as Ruth Gassner explains:

"Dr. Fink saw the need, he was very aware of the need of some of the patients that came here, who said that they want to go back home, and if they had support at home they wouldn't come to the hospice. It came from the patients. And he had a dream and he talked about that, I must say home care is not my part, but he insisted and he raised the money for home care with Professor Penchas who was the General Director of Hadassah." (74)

Helen Englesberg, one of the first nurses in the hospice who later joined the home care service, and Judy Yoran, the home care social worker note that the home care was set up to offer a 24-hour on-call service for patients and their families. Helen Englesberg explains:

“They can call...each family has a specific nurse that’s their nurse, but the other nurses will come to them, be there on a day when the nurse is not there, and then they’re also on-call at night and on the weekend. So any time of the day and night they can call to get an answer [like] you know, ‘should we give more pain medication?’”

The hospice worked to create a place of empathy and trust, with staff keen to explore different therapeutic approaches to improve support for patients and their families. Social Worker Malka Yehezkel describes some of the very successful initiatives tried over the years for adults and for bereaved children, some of whom later as adults, report great benefits:

“We’ve tried all kind of things during the years, like group work here: we had an art therapist working with us and we tried to do groups with the families here, and it didn’t succeed very well. It was an open group; every week different people came. But I felt that families prefer the one-to-one. Sometimes...the family sit there so I join them and we sit together, so it’s like a group. ... But group work after the death of the patient, maybe I would like to do more support groups? A few years ago we did group work in Tel Aviv. Ruthie [Gassner] and me, a nurse and a social worker, and the group was of one nurse and one social worker from hospices and the home care, and we opened a group here for children: nine to twelve, children of patients, a support group for *after* the death of the parent. And it was a small group but a very good experience for us.” (75)

### **Nancy Caroline Hospice of the Upper Galilee (HUG), Rosh Pina**

Founder of HUG, physician Professor Nancy Caroline became interested in palliative care in the course of her pioneering work training emergency paramedics. In the late 1980s she went to Tel Hashomer Hospice to train in palliative medicine with Alexander Waller, and to gain practical experience. She left Tel Hashomer in the early 1990s to establish her own home hospice which opened as the Hospice of the Upper Galilee (HUG) in 1994. She died in 2002. The multi-professional team has been led by Medical Director Dr. Jim Shalom since 2001, with the emphasis on offering a range of therapeutic skills to cancer patients and their families, The team includes physician and homeopath Dr. Eyal Goldberger, Dr. Mari-

anna Zrobliov, Dr. Ehud Barav, specialist oncology and palliative care nurse Yael Bleich, nurses Mazal Nitoker, Liora Aloni and Meira Gerlick, and social worker and family therapist Yaniv Ben-Shoshan. The team also calls on volunteer psychologist Niva, art therapist, Leila and music thanatologist Adira. Some key aspects of the ethos that have, and continue to be, developed in this hospice are explained by Jim Shalom:

“As a policy, almost always house calls are made by two staff members. Usually it’s a doctor and a nurse, but it can be the nurse and the social worker, occasionally there’ll be even three. This was something that Nancy set up from the beginning. It’s logistically complicated because we’re often coming from different geographic directions. There are two separate reasons for this policy, one in order to improve patient care, and the second to provide support for the staff itself. When you have a very complex case that has different technical and emotional components and you’re alone you tend to deal with the technical aspects. You will be better equipped to go into the more painful, less quickly available solutions if there’s another person there. In that respect a visit of two facilitates comprehensive and intimate care. A visit by two staff members, especially if it is a difficult visit is easier on the staff and helps prevent burn out, rather than a single staff member going to the visit alone. So this policy both works to the benefit of the family, and I think it also works to the benefit of the staff. It also usually necessitates less frequent visits. Furthermore, I suspect often when it’s a physician and a nurse there’s an element of psychological balance, a parenting model, where one person can deal with the more, the drier, technical, fatherly-type stuff, and somebody can sort of be more of the hugger. ... I think another thing that has become important, something that was very important for Nancy, and I think we’ve tried to maintain right from the beginning, is aggressive symptom control. We’re striving—we’re not quite there—to be able to evaluate in our charts too so that one can take a symptom, score it and then see what happens over time.”

The hospice also aims to provide reliable and varied sources of information by which to support patients through treatment and at the end of life, and in 2005 started creating a small library, as part of this process, explained in more detail by Jim Shalom:

“What happens all over the world, and also here in Israel, is that when people are dying with cancer, they try, they are looking everywhere for hope. So besides taking the orthodox treatment of chemotherapy or radiation, they go to all kind of healers, serious and charlatans and they spend a lot of money for these things and traveling very

big distances for this. So Nancy's dream, which we share, is that we should be also a center for information of this, not just treating the dying patient, which is the main field of the hospice, but also supporting, giving advice in all the fields related to palliative care. So we have many dreams also of having a place, a center, not just going out there in the field but having a place that will be a center for these kind of services. We are far away from that possibility but that's the general direction. At present in order to help patients who are looking for support, we are in the process of setting up a small library to give books on the field that could help someone deal with this stage of life." (37)

### Negev Palliative Care Services

The service was established in 1991 by Professor Pesach Shvartzman, a family medicine specialist, originally as a home care service for adults in the city of Beersheba. In 1994, Dr. Yoram Singer, also a family medicine specialist, joined the service and developed an extensive home-based service and a hospital consultation service for adults. He describes the development of the service:

"The home hospice team was started by two physicians and a nurse—and they built it according to [the US] model; in order to get home palliative care, you have to sign a consent form by which you really do sign the fact (a) that you realize the fact that you have a life-limiting disease and (b) that you are not going to get any kind of active treatment. Now nobody in this culture in the Middle East anywhere was willing to sign that kind of consent form, so there were about three patients, all of whom were American or British people, and that's how the thing worked. After a year and a half the staff resigned and Pesach [Shvartzman], who had just come to Beersheba, asked me to take over this and I said to him, 'No way,' you know, I was just setting up this very difficult initiative, trying to set up a teaching clinic against all odds and it was enough for me to do that, and I said to him, 'I'm sorry, there's a limit,' and he said, 'No, it's good for you and it'll be nice and interesting and we'll do it together,' really tried to convince me but I said no way. And so they took somebody else and it was a complete failure, it really almost disintegrated then. Pesach came to me again, he said, 'Listen, we've tried it and it doesn't work. Why don't you give it a try? Try it for three months, if you don't like it we'll find somebody,' and after two weeks I was completely sucked in and that was that, and since then we've been really doing it together.

"The service has really grown quite a bit now. It began against all odds because it's not part of the basket of services and there's no initiative, no reason why to develop

this kind of service because it doesn't even save money because of the way the health system works. We were really having a very, very difficult struggle. We started off and now we have a service consisting of three home care units and one mobile unit. The home care unit, one is in Beersheba, which is the main one and it's the biggest one, and we have 24 patients ongoing at all times. We have the meetings at the [community health] center where Pesach works. [The service] is a joint initiative of the University, the Division of Health in the Community in the Faculty of Health Sciences, and the HMO, and actually we get a little bit of funding from the Israel Cancer Association as well. Part of our post, well one half of our nursing posts and a half of our doctor posts are financed through this."

The hospice has developed working criteria, and has an ethos of maintaining personal contact with the patient as Yoram Singer explains:

"One criteria for working in our service is either you must have a position in the service or you must be a resident—we don't have any doctors who are not part of the service doing calls, because the physician or anybody who does any kind of call duty must be at that Thursday afternoon meeting to get input, and we don't want somebody to sort of go to the patient and start saying, 'Well, there's nothing for me to do, go to the hospital.' That's not what we're about. We have our patients, we have this personal contact which is absolutely essential; otherwise it won't work." (15)

### Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center, Jerusalem

In 1994, the Sha'are Zedek Medical Center called on oncologists Dr. Nathan Cherny and Professor Rafael Catane to set up a service for cancer patients, to include a program of integrated oncology and palliative care. Nathan Cherny takes up the history:

"Professor [Rafael] Catane was the first Chair of Palliative Care and he is now Chair of Oncology at the Sheba Medical Center [in Tel Aviv]. Initially the service was an outpatient consultative service and over the years the program has grown. Two of us are both oncologists and palliative care physician; one of them is Dr. Ora Rosengarten, who also coordinates the Jerusalem Home Hospital (the home care program for the largest of the HMOs in Jerusalem). In terms of the palliative care team since 1995 we've had a palliative care nurse; she was initially funded by a philanthropic grant, and since 1997 she's been on staff and we've had funding. We also have a research and education coordinator whose name is Rama

Sapir. Her background is that she's a clinical pharmacologist and together she's been a key player in research and in terms of developing educational publications in Hebrew but also translated into Russian and now Arabic; the management of pain, the management of symptoms, the management of post-operative pain which have been very widely disseminated."

An important aspect of the service has been the dedication of the team to address the need for the relief of suffering in patients at the end of life. The team works to improve pain relief and symptom control, conducting ongoing research and thereby constantly refining good practice, and also by developing psychosocial support. The initiation of spiritual counseling is part of the overall ethos of the service. Nathan Cherny explains:

"When I started in Israel, although there was a rabbi in the hospital, there was no tradition of chaplaincy organized spiritual care and this was clearly missing from the program. We had a limited, a couple of volunteer chaplains who'd come and gone but not very successfully. Partly because of cultural issues, and there was some degree of skepticism as to whether Israeli patients had a lot of spirituality. In 2002 Jonathan Rudnick approached me; he was a young rabbinic student who was interested in chaplaincy, and I said we were interested in taking him on but only after he got formal training. And he went to the States and did the thing called Pastoral Care Program and came back and started working on a voluntary basis, initially once a week. We introduced the service with a degree of skepticism on the part of some of my colleagues but from the outset it's been an enormous success. Partly because of his specific skills, not only interpersonal skills and religious skills but he is also multi-lingual, speaking Hebrew, English and Russian, remembering that there are a million Russian immigrants in Israel. What we saw through that experience was that there was a huge need, a huge yearning for it and that we found we were able to spiritually engage patients across the entire sociological spectrum, from the ultra-orthodox to modern orthodox, through secular, Christian, Moslem in a very productive and rich way, and it's really been one of the turning points in the development of the program. There is good cooperation between his work, the social worker and the psychologist without competition over patients. There are different issues being addressed and good communication between the services. Based on that initial experience on a volunteer basis we applied for funding from the New York Jewish Federation, and they gave us a grant to make Jonathan's position a full-time position and to start an internship program and this is what Jonathon has described to you. And besides the clinical program here he's put in a lot of his energies teaching

about the concept across the country, and the next stage of our program is to get funding to take on interns who will see it into other institutions. Not only to train interns but you need to train staff and to socialize them into the concept of this aspect of care, which we strongly believe is an important part of care." (13)

Rabbi Jonathan Rudnick describes the ways in which the spiritual counseling supports not just the patient but also the staff:

"We're trying to learn about how [this kind of approach] happens here, in order to try to help that happen in other hospitals, and part of it is clearly how the staff related to it. The whole other issue, in terms of the staff benefiting from this for themselves, for the spiritual care that the staff need, is a bit more difficult conceptually but I think that in general not just in spiritual care many people kind of feel like the whole issue of self care, like everyone says, 'Yeah, we need to take care of ourselves but lots of us don't do it so well.' But seeing this as something that is an important resource and something they can help in terms of the care for patients and families; the whole staff went along with this. And slowly and slowly [staff] started referring patients, in a sense of it being very slow and organic which is one of the important issues that Nathan emphasizes in terms of changing and developing the culture in the hospital setting in Israel where this is seen as OK, positive and something that the staff will want to support because it helps them as well." (14)

### Milton and Lois Shiffman Home Hospice in the Valleys

The hospice is one of the few services owned by HMO Kupat Holim Clalit. Founded in 1999 by nurse Mali Szlaifer, the hospice took over the work of the (now closed) Afula Hospital Home Care, on the retirement of the Medical Director Isaac Kersz. Mali Szlaifer explains the aims and ways the service has developed since 1999:

"For terminal patients I really felt that we can not do too much, and the needs were very large. The problem was that nobody was really in charge of that and the community send them to the hospital because they already paid for it, and they don't know how to manage their symptoms and things like this. The hospital sent them back home and the people were very miserable—really... Sometimes they give them something, or here or there, but didn't help a lot, and then they sent them back to the hospital and the hospital sent them back home. The vision of our hospice when we were establishing, is to provide excellence—not good but excellent palliative care for patients and family, and also to be one of the

leaders in palliative care in Israel, and to ensure that high-quality standards of palliative care services will be accessible to all patients suffering from progressive diseases—see that I’m not using the word ‘cancer’...in our hospice we will see other diseases...but we see very few referrals [for other illnesses]. In the beginning, the American partners (the Jewish Federation of Detroit) agreed to pay for three years. We are in the sixth year, so they decided that they will give for another three years but smaller amounts of money, and maybe I’ll have to close some of those regions.

“Staff satisfaction [is important], because one of my concerns at the beginning was that nobody works for the hospice a full-time job, everybody works very part-time, so I was afraid that, OK, this is not important and so on. But what happened over time [although they said] ‘it’s very bad time’ but they ‘see this as the quality work,’ as the nurses say: this is where they can magnify their profession. Because the district is very spread, one of the options was that I would take a nurse, for example, and she would be traveling most of the time because she must go from here to there to there to there—so I decided to take nurses or physicians who live in the region, a very small region, but that they can cover this region in 10-15 minutes of driving, and for example a nurse can have between one and four patients. [She is on call] 24 hours a day, all year. If she is not able to go to the patient, in every region there are two nurses, and then she will refer the patients for the other nurse, and sometimes today what happens is, if the nurse goes on vacation the doctor is on call for the patient because they build a very strong relationship in their team.

“In Israel, as I told you, in the beginning the Jewish Federation of Detroit gave us money to make a partnership, but in the Arab city they have no partnership, and I felt very bad because I felt like it’s some kind of discrimination, and I ask them that it doesn’t look good that we only give treatment for Jewish people. And they think about it and in Detroit they also have a very large Arab community and they want to improve the relationship between the Arabs and Jews so this also met some agenda of theirs. They give me the money to open the hospice in the Arab city of Nazareth, and then I was in the United States with an Arab social worker but she was working for the hospice of us here, and we made some projects together with the community of Israel and the United States. OK? So this is what I was writing about, you see, that sometimes when you are talking about mutual issues that are important for both communities and you are not talking about *peace* but those things that improve peace and understanding because, you see, we are people the same.

“So the goals were to provide high-quality culturally and religiously tolerant palliative care and train professionals from the various religious groups emphasizing the ethnic diversity of patients. And patients and families stated in this satisfaction questionnaire that the spiritual and cultural differences were appreciated and respected, you see that and this unique project demonstrated the feasibility of multi-religious collaboration in palliative care is a potential to promote understanding and peace.” (22)

### Jerusalem Home Hospital

Founded in 1991 as an HMO-run service, the Home Hospital was established to provide “hospital”-type care at home for patients with a range of acute and chronic illnesses, including palliative care at the end of life. The service is unusual because from the start palliative care has been offered to patients with a range of illnesses, not just cancer, and also the service provides palliative care for children at home. Medical Director Dr. Jeremy Jacobs explains:

“We’ve got, we have about 25-30 patients, full-time ventilated patients at home... with tracheotomies, and home ventilators the size of a shoe box. They’re at home, most of them are in home hospital; the minority manage to do without us.”

The service was also encouraged by work with heart failure patients at the end of life to ensure an effective home care service that would benefit both the health service and patients by preventing recurring hospital admission. Jeremy Jacobs continues:

“We discharged a lot of patients at one stage and we found that the heart failure patients went back to the hospital very significantly, so that we persuaded our bosses to reallocate funding in order to open up the service again. We have started a pilot service that’s focused on heart failure patients. Whereas in the past we have always waited for patients to be referred to home hospital, with the heart failure patients who are home bound/bed bound with recurrent readmissions to hospital we are actively seeking out patients to admit to home hospital. We’re going to take them in and give them the service for as long as they remain at the level of heart failure. We’ll keep them for a long period of time, with a nurse practitioner going in and a doctor going in, and see if that really keeps them out of hospital or not.”

The service continues to emphasize the importance of palliative care provision and employs a part-time palliative care consultant Dr. Ora Rosengarten and a specialist palliative care oncology nurse, Yonat Lamed. The Home

Hospital, as a concept and in practice, has proved both efficient and well-regarded and the nature of the team and the way they work have changed since the hospice was established, as Ora Rosengarten explains:

“Some 20 physicians work today in the Home Hospitalization service and provide the best possible care to the patients. Most of the physicians have been working with us for a long period; they have acquired good experience in palliative care, and they do their best to respond to patients’ needs 24 hours a day. Along with the nurses, we provide all services for end-of-life care—as much as can be done in the hospital setting, allowing the patient to enjoy the home without compromising the quality of care. The work done by the team of the home hospitalization is very difficult and only those really devoted persist in this work.”

An important part of the service has been to develop the supportive role of nurses for families in the home care setting. As Yonat Lemed, specialist nurse explains:

“A big part of the nursing work actually is supervising nurses, and the nurses themselves, to guide the family, it’s a big part of our role. If they get infusions they are taught how to change the bags, sometimes even with the sores the families are taught how to treat and change the bandages and everything; pain medication, of course. And we have to prepare the family what’s going to be, I mean, if we know already what is the deterioration of the patient, we have to start to prepare the woman, the wife, what she can expect to see, and what are convulsions and what are etc, and not just using those high words. Then it’s like we prepare her for what she will meet, will see, and then what to do if there’s something else, what will happen. This is really a big part of our role to do, the nurses.” (24)

By 2002 the Jerusalem Home Hospital had built its capacity to provide care for 450 patients at any one time. However, funding is always precarious, and the service was severely tested in 2002 when over two months, due to unexpected funding cuts by the health insurer, the service was forced to reduce the number of patients to 150, prioritizing cancer patients needing palliative care. A consequent sharp increase in hospital admissions prompted the insurer to acknowledge the cost effectiveness of home care and to restore some of its funding. By 2005 the service had managed to increase capacity back up to 300 patients.

## BEREAVEMENT SERVICES

Formal bereavement counseling is being developed in some services: the Ina and Jack Kay Hospice, and from 2005 at Tel Hashomer (76). In 2005 Negev Palliative Care Services started to develop bereavement counseling through Ma’agan House, Beersheba. However, most services offer some element of bereavement counseling that builds on well-established informal support already provided by the service prior to a patient’s death. Bereavement support may, as for instance at HUG, include one or more members of the whole team, or in other services tend to be taken up mainly by social workers or psycho-oncologists. Malka Yehezkel, the inpatient social worker at the Ina and Jack Kay Hospice, Hadassah, describes how she supports the family in the first stages of bereavement:

“After the death of the patient I sometimes go: first I go to the visit of the ‘shiva’; the Jewish have the ‘shiva’ [seven-day mourning period immediately following the burial] (77), the Moslem have three days, so I go to visit at this stage...I open the door to continue this follow-up if they want. Sometimes they are ready to come back here [at the hospice] and meet me regularly. At the beginning when the patient is here it’s not a regular meeting, every day I go up, I see them here or we meet. Afterwards, with the follow-up, it’s regular meetings, like in a clinic, it’s very different, that part. And I’m ready to go to their home if they feel it’s too difficult to come to the hospice again.” (75)

Other services will usually try to offer some bereavement support but may depend on volunteers being available. For example in Kiryat Tivon as Ilene Ora Cibulski explains immediately following the patient’s death:

“We do very little. [But] we always go to the seven-day mourning period [shiva]. We’re always there immediately after the patient dies. We call up or make contact [for] 30 days—30 days is usually, it’s a sort of type of mourning period [sheloshim]—and then whoever was in direct contact with the particular family calls about once a month until six months. Sometimes there are visits—it very much depends upon the particular volunteer (46).

## PEDIATRIC SERVICES

Palliative care services for children have developed slowly since the 1990s. For a few years there was one dedicated, though small, inpatient unit at Chaim Sheba—The Marion and Elie Wiesel Children’s Pavilion—but a change in staff in the 2000s meant that this unit developed a greater emphasis on curative care. There are two home care hos-

pice services able to care for children (Jerusalem Home Hospital and HUG). However, as pediatric oncology nurse Ruth Gassner notes:

“In oncology pediatrics, mainly when children die they stay in the hospital. From my experience I don’t believe that you can open an inpatient hospice for children, I don’t think that. Not even one parent would give up treating here, I mean treating, giving chemotherapy, etc to the children, I don’t think so. Usually they give it until the end. Very rare that they take the child home and he dies at home. It’s not so often.” (78)

Professor Pesach Shvartzman, who has helped to develop the pediatric palliative care consultation service at the *Soroka Medical Center, Beersheba* agrees and continues:

“Children are another issue, you know. [For] children, what we lack, what we don’t have is inpatient care, and we are doing our best to get a contribution to have an inpatient department. Now our children, you know, we have some children at our palliative care unit, usually children culturally—and it might be a Jewish culture—although we have many of the children who are Bedouins, usually children die in the hospital. It’s very difficult for parents to go home and let the child die because it might be obvious that the old people die, it’s not obvious that children have to die, so I can tell you that there are not many families in whom we could take the child out and take care of him at home. ... We have about four or five children dying each year and of course, just having...I usually work with the social workers of the pediatric oncology department, so there is not...what I did I just first of all trained the department themselves to do something by themselves and just give them the support and usually I used the resources of the pediatric oncology department because, you know, just to have a few people—five children a year—it’s problematic when you talk about cost-effectiveness.” (16)

Because families rarely request home hospice care for children, since the late 1990s in response to these very different needs of dying children and their families, pediatric services have tended to develop hospital-based services rather than home or specific hospice services. For instance, there are currently hospital consultation teams and hospital-based support groups for families within pediatric oncology units at several large medical centers.

### DROP-IN CENTER

The only drop-in center in Israel was established in the early 2000s, Ma’agan House, in Beersheba, run by Negev

Palliative Care Services as a charitable venture funded by an independent, overseas benefactor. Dr. Yoram Singer explains:

“Ma’agan House is a community house whose function is to support cancer patients and their families. It’s like a club, where they have all kinds of activities for cancer patients and their families. There are also group therapy sessions, and there’s an art therapist and a music therapist who come. They have lectures on all kinds of, not medical issues but sort of bringing together cancer patients—not only terminal cancer but cancer patients and their families under one roof.” (15)

The center is organized by a social worker with a group of trained volunteers able to offer a range of supportive and creative therapies.

### CHANGES IN SERVICE PROVISION

Since the late 1990s, financial and staffing difficulties have resulted in closure of some home hospice services such as the Haifa Home Care Hospice in 2003, the reduction in provision of services as at the Jerusalem Home Hospital in 2002, and the shift of emphasis from palliative care to more curative-based pediatric care at the Marion and Elie Wiesel Children’s Pavilion when dedicated palliative care staff moved to other locations (79).

Established in January 2006 by Kassim Baddarni, a registered nurse, the Al-Taj for Health and Heritage Association is a charitable, volunteer-run home hospice service in Galilee, north Israel (80). A multi-disciplinary team of two full-time and 10 part-time volunteer health professionals and lay support staff are able to undertake home visits to over 20 cancer patients a year. The service works with patients of all ages and at different stages of illness.

Various other new services have also been set up in the last few years within existing organizations; for example, the mobile desert unit started in May 2004 at the Negev Palliative Care Services, the inpatient unit and the spiritual counseling service at the Cancer Pain and Palliative Care Unit at Sha’are Zedek, the current expansion of services at the Hospice of Upper Galilee, and the development of palliative care services at the new Davidoff Oncology Unit, which now incorporates the Beilinson Unit at the Rabin Medical Center.

Since the 1980s, with the support of the Israel Cancer Association (ICA) and the Israeli Association of Palliative Care (IAPC), dedicated services have been developed in many areas of the country, including an extensive community nursing service and regular training programs.

## HOSPICE SUCCESS STORIES

### Tel Hashomer Hospice

Alexander Waller, Medical Director, writes:

“Tel Hashomer Hospice has not only provided good and appropriate treatment to patients in the terminal stages of cancer, but has also strengthened the awareness of their particular needs—among the Israeli medical community and Israeli society at large. By its successful example the Tel Hashomer Hospice has stimulated the establishment of additional hospices throughout Israel. Ours was a truly international effort, for since our very first days we enjoyed the friendship, advice, and support of colleagues abroad, most notably our English friends and especially those from St. Christopher’s Hospice.” (8)

### Ina and Jack Kay Hospice

Ruth Gassner, Director, highlights one important aspect of the success at the hospice at Hadassah:

“Avoiding burnout and keeping your good staff. I read in the literature that in hospices every two or three years nurses are rotating, that’s exactly what I wanted to avoid, so how do I avoid it? [Harriet Copperman] said that burnout comes only from hard conditions, not from hard work, and, you know, during the years, now I can say because now I’m almost twenty years here, that she was so right. Look at the nurses, they are still with me, most of them—some left because they left Israel, some left for the north—but most of the nurses are with me.”

Malka Yehezkel, inpatient social worker agrees and also notes that:

“This multi-disciplinary work is, I think, one of the keys of doing the best job here, and I know it’s not everywhere, we appreciate it very much.”

Judy Yoran, home care social worker describes success at the patient level:

“When you help them when you see a patient that suffers, the day after he has a very tiny smile, small, a smile; that is a huge success....I think we have to, we have to see our little steps as our successes because there are a lot of battles to fight, I think, around the, what society sees as a hospice, you know, we still, people see us as a place where you come to die and you don’t leave, and so we are all fighting that when you try to explain to someone, you’re trying to give them quality of life, not only end of life, that’s a very big change of mind. But I think also you

can add to your successes starting to educate the rest of the hospital about what palliative care is. They’re called in by nurses in the internal medicine department, the nurses are sometimes in the middle of the night consulted about how to help someone with pain, and the doctors are educating other doctors.” (10)

### Cancer Pain and Palliative Medicine Service, Sha’are Zedek Medical Center, Jerusalem

Nathan Cherny, oncologist and director, identifies some key developments as markedly successful, and includes research (among many other strengths in the service) and the dissemination of this work through ESMO to the wider community as a particular important part of the service:

“Since 1994 the key things have been, the four biggest things have been getting the position for a dedicated palliative care nurse, the second was getting the nurse and research assistant, secondly getting more staff, having more help, then the development of the inpatient service and finally the development of the chaplaincy service. In terms of research and education we’ve had a long history of involvement, looking back at issues, looking at attitudes and practices and also issues of specific interventions. When Professor Catane was head of the department here, at the time he was the national representative for Israel on the board of the European Society for Medical Oncology, and he suggested to them that they form a task force to approve the integration of oncology and palliative medicine all across Europe and this was approved by the Board. Since that time I have run this task force which has had a very strong ripple effect in the organization. ESMO have adopted a series of policy statements on the role of the oncologist, and minimal standards for cancer centers in the delivery of palliative care. It surveyed its entire membership on their practices and that’s been published and it has set up an incentive program to award centers of excellence in the integration of oncology and palliative care and this is to try to encourage centers across Europe to really look at this issue and it’s been a very successful program in ESMO and is widely publicized the organization on the front page of their website and it’s early to say but there’s definitely a ripple effect and an awareness that’s been generated through this intervention and this whole program has come out of this department.”

### Negev Palliative Care Services

Dr. Yoram Singer describes the successful developments as providing a vital service for patients as well as providing opportunities to train physicians:

“Many of the people, by the time we come on, they’ve been *so* disillusioned and they’re *so* angry at the health system that it may take a week or two for us to regain their confidence in any kind of health, any kind of system which has to do with health, because they’ve, you know, had a recurrence and *another* recurrence, and finally the oncologist has called them together and said, ‘Listen, there’s nothing more we can do.’ Then they send them home, and there’s nothing more horrendous for a family than to sit at home and feel that there’s nothing more can be done. And then we come and we say, ‘Well, we have, there’s lots we can do.’ ‘How’s that possible? I mean, in the hospital the Professor said there’s nothing, how is it possible that *you* think you have [something]?’ And then we say, and we start doing, and suddenly the patient feels better. Wow, it works, and it makes a whole difference because then the patient suddenly has enough energy to be able to do all these things that he has to do, you know, closing, forgiving, asking for forgiveness, the whole thing. The important point in all this is how to teach? We have to convert the non-converted. I can tell you that ninety per cent of the [family medicine trainee] residents when they start are *absolutely* petrified. ‘What is...how are we going to get...?’ I mean, you know, residency is not a very easy thing anyway, but ‘How are we going to deal with this issue? I don’t know; this is too much.’ And very often they come up with most amazing excuses why they just can’t possibly do this kind of thing, but by the end of the nine months [training] they’re pretty good at it, I must say. So I think it’s absolutely important and you can see if somebody’s been through this program, they will call up and ask for advice because they know that there’s something—they can’t always remember or whatever, but they call up and they know where to look for advice, they know that it’s possible to, and you can tell the difference, I mean, there’s no doubt whatever.” (15)

### Milton and Lois Shiffman Home Hospice in the Valleys

Mali Szlaifer, Director, explains some of the success is due to the way the team is trained and works together:

“I think what is the special thing in our hospice here is that all the education we are doing is on a multi-disciplinary basis. It means that even the social worker learns about medication, and the Edmonton [pain assessment scale] and everything. So she supports also if she goes there and the patient is in pain. She’s not supposed to treat the pain but to call the doctor, she doesn’t have to treat, but assess, yes.” (22)

As Mali Szlaifer notes this has resulted in everybody in the team being involved in assessments and then respond-

ing according to what is required. Dr. Amitai Oberman, Medical Director, highlights the staff commitment:

“They don’t do it just for the salary; I mean you have to like what you do. So there’ve been rotations and some people came and some people left, and we basically ask people, ‘Are you interested, there’s money, but are you interested in coming to work with us?’ Because there have been rotations, although we didn’t plan it this way, many of the nurses within the Nazareth region have been exposed to palliative care. So we all know one another and I feel at home here. It’s less...it’s more complicated with the physicians because I don’t really see them too often—I talk to them in conferences, I talk to them over the phone—but with the nurses and the social workers there is wonderful liaison; I can tell [the social worker] Shauki, ‘Tell the physician to do this,’ and it’s done.” (42)

### Jerusalem Home Hospital

Medical Director Dr. Jeremy Jacobs reports two important elements in the success of the service:

“Everyone’s very pleased with our service here, which is not a surprise. As regards the quality, what’s important is the communication, that’s what makes or breaks the service; in addition to the medical or nursing or the professional side of it, probably what makes it successful and ensures the patients stay at home is the level of communication. And the more communication the better the service is. And it’s good for our bosses because supposedly it costs much less than being in hospital and we consistently show that it reduces hospitalization rates. So it is financially viable.” (24)

### Nancy Caroline Hospice of the Upper Galilee Hospice of the Valleys

Medical Director Dr. Jim Shalom describes some aspects of the hospice’s success:

“We have quite a good connection with the pain clinics in all the main, big hospitals in Israel, and we have one patient which we are going to present next week, in a seminar, that he is with us for more than three years, he has a spinal pump, and we do all the...all the refilling of the pump, we do it by servicing at home, so we try to do, that’s one of the things that hospice is doing extraordinary things, many different examples, so I think we are quite good at it, at trying to treat each case as, each case individually, seeing the needs and trying to improvise sometimes.”

Yaniv Ben-Shoshan, Social Worker, explains the success of the patient/staff approaches:

“I think that, I think all of us receive a lot of, from our work. For me it’s a lot of life, of a sense of life, and a love of life, I find in the family and the person, not in all the person, not all the patients and their families, but the process that I go with a person and with them to find some [meaning] in their time of life, in *this* time of life, and I with them, it’s a lot.” (37)

### Home Care Hospice of Kiryat Tivon, Northern Israel

Dr. Ilene Ora Cibulski describes the greatest success from her perspective in Tivon:

“In Tivon, we always had our training of professionals and nonprofessionals together, and we always used the professionals to teach their particular thing. I met the most wonderful people in the world. Not one, not two, I’m talking about *dozens* of very, very special people, dedicated people, knowledgeable people, responsible people, people who would crawl on their knees in order to get to a patient. It wouldn’t make any difference if it was two o’clock in the morning or on Yom Kippur, it wouldn’t make a difference: if the patient needed them they would be there. And that’s a privilege, you know, how many of us have chance to meet people like that?” (46)

## LIFE/ORAL HISTORIES

### Aliza Yaffe, Head Nurse, Israel Cancer

**Association:** *interviewed by Amanda Bingley, 13 May 2005. Length of interview: 1 hour 20 minutes*

In this interview Aliza Yaffe describes her work with the Israel Cancer Association, developing specialist nurse training and community home care:

“When I came to the Israel Cancer Association I was working in a general hospital in Tel Aviv and I was teaching at nursing school and I already had experience of treating the patient with stoma but I didn’t have the formal education in stoma care. And later on I went to the United States in order to have specific education. And that was my job description. But stoma care is not the only thing that they should need, and not everybody has a stoma, so gradually we developed in the Israel Cancer Association some nursing services and some nursing education. I think it was kind of bolting things together. I went to the first Cancer Nursing Conference in London in 1978 when Mr. Bob Tiffany from the Royal Marsden, he said, ‘We

need an international conference.’ When I returned from there, I went to the General Director of the Israel Cancer Association, Miriam Boaz. She said, ‘OK, what do you think we need here?’ Then I said, ‘we need some education for nurses in cancer, nursing not only the general, the general nursing education that we get.’ There were specific courses on midwifery—not like in England, the nurses study differently, but postgraduate courses, midwife courses. Then we said we need also something like that in cancer nursing, and that was the first step doing something different from stoma care, starting a course in cancer nursing.”

**Dr. Nathan Cherny, co-founder and Director, Cancer Pain and Palliative Medicine Service, Sha’are Zedek Medical Center, Jerusalem:**  
*interviewed by Amanda Bingley, 4 May 2005.*  
*Length of interview: 1 hour 19 minutes*

Nathan Cherny describes his early interest in medicine and his eventual training as a physician. He explains that he was made powerfully aware of the needs of cancer patients and palliative care partly through his own experience of illness and partly through the impact of seeing two documentaries on St. Christopher’s Hospice and another on the work of Elisabeth Kübler-Ross, whom he later met, and then caring for a young patient who was dying. These influences led to his training in medical oncology where he was struck by the lack of awareness in other oncologists of palliative care: “When I started my training in medical oncology one of the things that struck me was that the residents around the hospital really knew nothing about palliative care and this was a problem in terms of care round the wards and I approached the medical school to see if they would allow me to teach palliative care to the students on the internal medicine rotation and this is now 1988/89, and that was supported and I wrote part of the palliative care training program for Monash University and I taught that through the rest of my fellowship in oncology and you know the preparatory work that went into preparing that material gave me a lot of background into palliative care and the clinical skills of palliative care and led me to the next decision point which was in seeking a fellowship, to seek out a fellowship in palliative care. I went to talk with Kathy Foley. So you can see there have been multiple steps along this way, and when people ask me who inspired me, no single person inspired me, there was the very brief exposure to the work of Elisabeth Kübler-Ross and then these trigger experiences with patients as a young medical student. As I have gone along the path there are people who I’ve found wonderful inspirational people along the way, certainly Kathy Foley and Russell Portenoy were

wonderful mentors to me when I was at the Memorial Sloan-Kettering Cancer Center. While I was there I was exposed to a couple of other people who had a disproportionate impression on me to the amount of contact, one was Derek Doyle and the other one is Ned Casson. Kathy and Russell in particular created opportunities for me to develop professionally to develop an interest in policy beyond just service delivery.”

In 1993 he arrived in Israel at the invitation of the Director of Sha’are Zedek to establish, with Professor Rafael Catane, the service at the center, which has proved to be a highly successful unit. He notes that in the course of his work in palliative medicine he has instigated research into pain and symptom control and the relief of suffering at the end of life.

**Jonathan Rudnick, rabbi, spiritual counselor, Cancer Pain and Palliative Medicine Service, Sha’are Zedek Medical Center, Jerusalem:**  
*interviewed by Amanda Bingley, 4 May 2005.*  
*Length of interview: 35 minutes*

Jonathan Rudnick talks about how spiritual counseling was initiated into the service and is currently being developed. He explains that his interest in bringing spiritual counseling into palliative care was supported by Nathan Cherny and other colleagues. He speaks about his specialist training in the USA, and how the service is now supporting the course he is teaching for others to train in this work. He describes how successful the counseling is proving to be for patients, families and staff.

**Dr. Amitai Oberman, Medical Director, Milton and Lois Shiffman Home Hospice in the Valleys:** *interviewed by Amanda Bingley, 10 May 2005. Length of interview: 58 minutes*

Amitai Oberman describes how his interest in palliative medicine developed out of his work in geriatrics. He explains how after his training in internal medicine in 1996 he went to the United States to do a Fellowship in Geriatric Medicine at Harvard. After two years of clinical training and a year of research, he was increasingly fascinated by the USA approach to end-of-life issues and treatment, such as the advanced directives and patient autonomy. This led to a two months palliative care training in an inpatient hospital-based hospice unit. On his return to Israel he continued, as a geriatrician, to be involved in palliative care, both in the nursing home system and in his work in internal medicine in one of the hospitals:

“Mali [Szlaifer] approached me and said, would I like to come and help out, because she knew of my interest in setting up the home hospice unit? Then I joined the Israeli Palliative Care Association and from there things began rolling very quickly and I became very involved, both on a local level setting up the services here, a lot of education, and on a national level meeting people, getting to know the system. Over the last few years we’ve been working in parallel lanes: one is the local hospice here and the other on a national level. I have to devote much of my time to the national level, setting up, getting to know people, bringing people together, setting up these big annual conferences, and also working on a regional level. When I went to work in Poria at the Geriatrics Department, originally there was an inpatient unit there which was a more skilled nursing facility, but I managed to get education for the nurses there, so until it was closed down a year ago all the terminally ill patients at Poria were moved over to my department, and we’ve got good staff over there. I’ve been involved with the EAPC from 2001 or so, we’ve had the poster, then I had some more posters; in The Hague I gave a lecture on palliative care and dementia. A lot of the work is devoted to the national level kind of stuff in order to promote palliative care on a national level. I’m very active in the Education Committee and the Health Services Committee, teach a lot, but also try to get involved as much as I can in doing true clinical care. In the kibbutz which I live in we had a couple of patients die at home. I wish I could have more time and devote more of my time to palliative care, which I don’t do enough. I could do more but these are the limits which I have.”

**Mali Szlaifer, Chair of IAPC and Hospice, Director, Milton and Lois Shiffman Home Hospice in the Valleys:** *interviewed by Amanda Bingley, 9 May 2005. Length of interview: 2 hrs 20 minutes*

Mali Szlaifer talks about the history of her involvement in the Israeli Association of Palliative Care (IAPC) and her election as chair of the association. She describes her work in the largest of Israel’s health insurers, Clalit Health Services, where as a trained nurse and regional nurse manager she organizes the provision of nursing services for patients at home with chronic illness. She relates how in the course of this work she became acutely aware of the needs of patients at the end of life and decided in 1999 to set up a palliative home care service. Drawing on her considerable management experience she negotiated with Clalit to fund the service and called on another IAPC board member and local geriatrician Dr. Amitai Oberman to join her in establishing the home

hospice. She talks about her determination to create opportunities in developing her own and her colleagues' knowledge and skills in palliative care through links with health care professionals in organizations in Israel and overseas. She describes her research and evaluation work in home care and her enthusiasm in developing the IAPC educational programs.

## HOSPICE TEAM INTERVIEWS:

**Ina and Jack Kay Hospice, Hadassah, Mt. Scopus, Jerusalem:** *team interviewed by Amanda Bingley, 4 May 2005. Length of interview: 2 hours 7 minutes*

**Ruth Gassner, co-founder and Director**

Ruth talks about her long history with the hospice, as co-founder and Director since the start in 1986. She trained in pediatric nursing specializing in pediatric oncology before she became involved in establishing the hospice. She describes how the renovation of the building and the setting up of the hospice was funded by American benefactors as well as the Kay family, and then she had to find staff to work there:

“I started to recruit some staff, and I did it on my own intuition. I didn't know what I wanted; I just knew that I wanted good people. What is good I don't know—now I know, then I didn't know. I made a few mistakes: I don't think too many, but a few mistakes I made. Those that weren't so good left, but very small number of people. Most of the staff which is working here in the hospice are people that started with me in '86.”

She talks about how the team has developed ways to best support patients and families and relates some of the challenges they have faced in their work within the inpatient hospice and in the community.

**Dr. Daniel Azoulay, physician**

Daniel Azoulay describes his work at the hospice, the ethos of the care, and how he came to work there. He explains that he was practicing general medicine in France and came to Israel to train in internal medicine. He began to work in geriatric medicine which started his interest in palliative care. Around 10 years ago he was asked to take the position as hospice physician in addition to his geriatric work at Mt. Scopus hospital. He discusses his dedication to working in palliative care, his enthusiasm for teaching and training other health professionals and

his involvement in seminars and conferences nationally and internationally.

**Malka Yehezkel, social worker**

Malka explains that she has worked at the hospice for around 16 years, following community social work. She relates the story of her introduction to the hospice:

“I was working in the community. I had a patient that I felt maybe should be in hospice and I asked the family and they were interested; her son was a doctor, and her daughter was a social worker. We got in touch. It was a good relationship with the patient... it was the first time I talked to someone about death and hospice—and I asked her what she thinks about it, and she said, 'I feel I need it.' And then I talked to the family and I called Ruthie [Ruth Gassner] and the patient was hospitalized here. I came to visit once... she was only here a few days; I came to visit only once. It was a time that I thought I need a change, a different kind of work in my profession, and it was the first convention of the hospice, three years after the hospice was opened, and you invited me to come. The first social worker, she said in front of everyone that the hospice is looking for a social worker to the home care, and I came to talk to her and I said I feel I want to be in the inpatient unit at the beginning, and that's how it started.”

She talks about the importance of how the team support each other and how much she loves her work.

**Judy Yoran, home care social worker**

Judy talks about her work in home care and the family support offered by the service. She explains how the work changes and presents different challenges, which reflect the ways communities and cultural groups have had to change in the face of the conflict.

**Helen Englesberg, home care nurse**

Helen talks about how she came to be one of the first nurses recruited to the hospice when it opened. She started nursing in London and was working in oncology before she was unexpectedly introduced to palliative care:

“I'd met Cicely Saunders many years ago when I was in London. I went to the Royal Free Hospital to visit a friend, and I'm looking at the noticeboard. I was working in oncology, and I see [there was a] Cicely Saunders' lecture; [I thought] that sounds interesting. I went to the lecture and I just fell in love with this whole idea. I said this is wonderful, this is what we need, this was in

1975, something like that. And then [Cicely Saunders] came to Israel and she came to Hadassah, she gave a lecture and I went to the lecture, and again I said this is wonderful and I was full of it all. And the years went by and I'm not in oncology any more, and I'm reading the *Jerusalem Post* one day and I suddenly see 'Hadassah Medical Organization...opening a hospice... contact Ruth Gassner,' so immediately I called Ruth Gassner. We arranged a meeting, she said 'I'll meet you, come to the hospice,' and she told me how to get to here, and she met me at the door. The place was empty, there was no furniture, I think there were a few chairs in here, and we sat. I remember exactly, we sat over here on those brown chairs, just a few chairs. We sat together and we talked and I told Ruthie about my history, she told me her history and I think I was one of the first nurses probably to be employed here actually."

**Jerusalem Home Hospital - team interviewed**  
by Amanda Bingley, 3 May 2005. Length of interview: 1 hour 9 minutes.

**Dr. Jeremy Jacobs, geriatrician and Medical Director; Dr. Ora Rosengarten, consultant in palliative medicine; Yonat Lamed, specialist oncology palliative nurse supervisor; Timna Zistling, head nurse**

Jeremy Jacobs leads the team discussion about the work of the Home Hospital and how the service is managed and organized. He describes the flexible approach they have developed in order to be able to care for patients with a range of complex illnesses. He explains some of the history of the service and how, because the service is run by the HMO Clalit, they have had to pay particular attention to balancing economics with providing good care for a large number of patients. Ora Rosengarten, Yonat Lamed and Timna Zistling describe some of the situations and challenges of bringing hospital-type care into the home with a wide range of patients. They talk about the importance of helping to reduce the physical, mental and emotional suffering for people at the end of life and how they try to do everything needed for the patient; offering such a wide-ranging home care service enables them to support many people to stay at home who would otherwise die in hospital. They sometimes have to deal with difficult ethical dilemmas but have proved the service to be both efficient and welcomed by patients and families.

Yonat Lamed explains:

"I started to work here something like nine years ago and today it seems so different from since I started. You know, at the beginning when I called a doctor and I said, 'Well maybe we do that,' and he was shocked, I mean, 'Who you are? A nurse?' and today we just work together, it's really a team and we advise each other and the doctors know that I know palliative care maybe more than many of them and they are willing to hear advice, etc and we just work as a team. You do need an oncology nurse who is palliative care oriented, you know, to be able to do it."

Dr. Ora Rosengarten confirms the importance of the commitment of those dedicated to palliative care:

"If you look at the doctors, really it's something that's very special, I think; like we have a surgeon in the service that's giving palliative care today. I think you can take a lot of oncologists who could learn from him how to deal with patients with their last days of life, really. They're really dedicated and devoted, they're devoted, it's more than dedicated, they're *devoted*."

**Nancy Caroline Hospice of the Upper Galilee (HUG): team interviewed by Amanda Bingley, 9 May 2005. Length: 2 hrs 3 minutes**

**Dr. Jim Shalom, Medical Director**

Jim Shalom talks about his involvement in palliative care and he also relates the story of Nancy Caroline, in whose memory the hospice is named; she was an influential physician in palliative care before her untimely death in December 2002:

"Nancy grew up in Boston, USA and from a very young age she knew that she wanted to be a physician, studying at Harvard. She got involved early on in her career in emergency medicine, and set up an educational program for paramedics and wrote a handbook called *Emergency Care in the Streets*. The paramedic program became nationwide and then was basically exported, certainly Israel uses paramedics and Canada uses [them] and other places. She came to Israel and started working with the Israeli Red Cross. At some point a physician friend of hers had terminal cancer, she was working during the last month and she found herself helpless not being able to help him. And that sort of caused her to change: she declared that she would never let that happen again, and she started going down to Tel Hashomer which is one of Israel's big hospitals and studied oncology. Then she met Alex Waller (head of the Tel Hashomer Hospice) and started studying, going down to the hospice there. She got very interested and learnt the subject well and she co-wrote

a textbook of palliative care with Alex Waller, based on their experience.

“Then she decided to set up a hospice and that’s where I met her. She tried to persuade me that the Upper Galilee needed a hospice. I said, ‘Nancy, you know, I’ve worked in palliative care in semi-rural Canada, and when I came here I was surprised at how antiquated things were; their hesitation about using opiates, the idea of not treating people at home or, if they’re treated in hospital all the very basic stuff, but that’s just the way it is here. Because when I was working that’s not only how the *hospital* practiced but the families, that’s what *they* expected: ‘They’re gonna give my father *narcotics!* I mean, he’ll become addicted to it.’ He’s gonna die in three days. So I said [to Nancy], ‘You don’t have to persuade me, I just don’t think that you’ll be able to get through the red tape.’ Well she did and she set things up and she had this way of getting people to agree with her. You could argue with her but it didn’t help because she always had the arguments to justify. But when I took over as the administrator it was a little bit intimidating and she didn’t interfere at all, nothing, absolutely nothing. There was a period of about, I took over in October 2001 and she died December 2002—never once did she have a word of criticism. She was just helpful and supportive in any way that she could be. And then we took care of her.”

### *Yael Bleich, specialist oncology nurse*

Yael Bleich describes how she became involved in this work at HUG nine years ago:

“I met Nancy Caroline in 1996. I first went on the oncology nursing course, a postgraduate course for one year. Then Nancy invited me to meet her and to see if I would work with her. She *was* the hospice [at that time], she did everything there; doctor, nursing, secretary, driver. She treated about, say, five, six patients at a time. I started to work with her and it was only two days a week, but more and more I left everything else and I did this work. Between all this more and more families and physicians and nurses, started to ask us to come to see the patient: and it grew and grew, and one more doctor came, Dr. Marianne, and then one more nurse, another American doctor, and then Nanny got sick and Dr. Shalom started work. Now we are about ten or eleven people.”

Yael discusses the way the team works to resolve pain relief and symptom control in collaboration with the oncology department, always with the aim to connect sensitively to a patient’s individual needs. Where appropriate, Yael will bring in the expertise of the team

art and music therapists (Leila and Adira) to support a person’s journey at the end of life.

### *Dr. Eyal Goldberger, physician and homeopath*

Eyal Goldberger describes how his interest developed in homeopathy and palliative care:

“After I finished my internship, I was interested in oncology and especially as a student I was always seeing the old patients, if nobody wanted to see them myself, I was not afraid of the real people. So when we had the opportunity to do the one-year course I went to the hospice in Tel Hashomer for one month and then after the course for one year I was mainly in charge of the home hospice, but also working in the department. They asked what was a young doctor at the beginning of his career doing with people at the end of their career. But it was a very, very important experience for me. Then I did an officer course as a medical doctor with the army, and then the Gulf War began. Afterwards I went to England to study homeopathy at the Royal Homeopathic Hospital. Even in the army I was interested in complementary medicine. For almost ten years I left the palliative field and was doing mainly homeopathy, teaching and working here [in a hospital]. Then my father-in-law had cancer; at the end of his life I arranged for him to go to Tel Hashomer, and I spent the last two weeks of his life with him there. I met people that I knew ten years ago. I said, ‘When I go back I must check what’s happening in palliative medicine in the north.’ A week later I had a message on my answering machine from Niva—she’s the psychologist—that I should call her urgently connected to Hospice of the Upper Galilee, which I never heard before. I said what a coincidence. Then I was in a kind of a turning point, I had to decide to start a new job in somewhere else...and I was ready to go into it. Very quickly it became the main thing that I am doing so basically I cut down my homeopathy but in this last two years I had to see how homeopathy is going in the world, I attend lots of seminars here in Israel, so it was a good time to do some kind of change. I enjoy the work. At first I was not religious and going to homeopathy from orthodox medicine, I also, through a long process of spiritual searching which were all over many other fields so I became religious here. I enjoy very much seeing the patient in their home, not in a clinic, and the team is very, very excellent.

### *Yaniv Ben-Shoshan, social worker and family therapist*

Yaniv Ben-Shoshan talks about how he became involved in palliative care and how this experience enriches his work at HUG:

“When my daughter was six years old she was sick of cancer for one year, and received chemotherapy in Haifa Hospital. Ten years after, when I work with our hospice patients, I bring with me not only my experience of my work, but also the family, own family experience.”

He explains the importance of the way the team works, where each member is an integral part and can refer to the other in any way that best supports the patient and the family.

### Negev Palliative Care Services, Beersheba

*Professor Pesach Shvartzman, pediatric oncologist and Head of Division: interviewed with Dr. Yoram Singer by Amanda Bingley, 5 May 2005. Length of interview: 45 minutes*

Professor Shvartzman talks about his palliative medicine research work, specializing in pediatrics and his role in setting up the first hospice services in Beersheba. He is trained in family medicine and this led to his interest in palliative care:

“When you look at palliative care and it’s actually very close to the way that family medicine works and actually I think if you look at the UK, a lot of GPs are involved in palliative care. It’s not just by chance, I think that the way of thinking, the way of looking at patients and not at diseases, the way of looking at the context of families, the way of not seeing the fact that you cannot cure everything as our own failure, but just as a fact that medicine cannot cure everything and just to recognize the fact that people die, and they will die. So I think that the way of thinking is not far off and actually I felt that probably it is actually pretty neglected in—not in the UK, but the UK is an exception I think—UK, Australia, Canada, the States, and probably that’s it, New Zealand maybe—but if you look at our country we have still a far way to go.”

He explains that he did some training in Canada with Balfour Mount at McGill University and conducts a research program as part of his own work as a Professor in the Faculty of Medical Science at Ben-Gurion University of the Negev. He is also involved in training in pediatric palliative care.

*Dr. Yoram Singer, Medical Director: interviewed with Professor Pesach Shvartzman by Amanda Bingley, 5 May 2005. Length of interview: 45 minutes. Dr. Yoram Singer interviewed individually: 1 hour 10 minutes*

Yoram Singer describes his commitment to palliative medicine and his diverse experience in Africa, where he was involved in setting up effective community medicine projects, and in Israel as a community and family practitioner before he became involved in developing the service at Negev. He talks about how the service is organized and some of the extraordinary generosity of benefactors and the ways in which he has managed to raise the profile of palliative care by working sensitively with multi-cultural communities in remote parts of the country. He explains how his previous work has both enriched and inspired the ways he and his colleagues are developing the service.

### Tel Hashomer Hospice, Chaim Sheba Medical Center, Tel Aviv (team interviewed individually)

*Dr. Alexander Waller, Medical Director: interviewed by Amanda Bingley, 8 May 2005. Length of interview: 45 minutes*

Alex Waller discusses the ways in which Israel has developed a hospice and palliative care service that is on a par with Europe. He talks about the early history of Tel Hashomer and the importance of the hospice in starting to raise awareness of palliative care and in encouraging the education of health professionals. He describes how Tel Hashomer influenced others, stimulating the opening of new hospices around the country. He explains his interest in education and the importance of exploring ways to improve the practice of palliative care; for example, the development of a multi-disciplinary hospice team that aims to address needs of the patient.

*Dr. Michaela Bercovitch, physician and researcher: interviewed by Amanda Bingley, 1 May 2005. Length of interview: 35 minutes*

Michaela Bercovitch describes how she joined the hospice in 1991 having arrived from Romania in 1987. From a background of great personal tragedy she was at first unsure that she could work in palliative medicine. However, during her work in the Rehabilitation Geriatric Department at Chaim Sheba she completed a six-month residency at Tel Hashomer Hospice and was subsequently inspired to take up a permanent post in the hospice as inpatient physician. She describes how much she learns about palliative care from the many patients she has cared for as a

physician. She talks about how the hospice is organized and her role as researcher, physician and palliative care consultant in the department of gynecology. She has seen the hospice through many changes, most recently the move to the new purpose-built unit, and she talks about some of the challenges they face as a unit and in the hospice movement. She writes about her involvement in developing and teaching palliative care training, and her work with the Israel Palliative Medical Society.

**Tamie Goan, nurse, Home Care Service:** interviewed by Amanda Bingley, 1 May 2005. Length of interview: 25 minutes

Tamie Goan explains how she became interested in palliative care when she was a dietician in a dialysis unit and went on to train in nursing, specializing in oncology nursing. She now organizes the nursing in the home care service.

**Sarah Rimer, social worker:** interviewed by Amanda Bingley, 1 May 2005. Length of interview: 20 minutes

Sarah Rimer joined the hospice as a part-time social worker for the inpatient unit. She talks about her interest in palliative care and her commitment to work with patients and families.

**Shulamith Werner, physiotherapist:** interviewed by Amanda Bingley, 1 May 2005. Length of interview: 20 minutes

Shulamith Werner is a retired university tutor in physiotherapy. She talks about her lifetime of experience as a physiotherapist and how she enjoys her part-time work at the inpatient hospice. She describes her dedication in supporting patients at the end of life and the ways she can help to improve their quality of life.

### Kiryat Tivon Home Hospice

**Dr. Ilene Ora Cibulski, sociologist and gerontologist, co-founder of the hospice and co-founder and retired chair of the Israel Association of Palliative Care:** interviewed by Amanda Bingley, 12 May 2005. Length of interview: 1 hour 13 minutes

Ilene Ora Cibulski describes her involvement and motivation in setting up the home hospice at Tivon. She was born in the USA and had trained as a sociologist and became increasingly interested in gerontology. She was inspired to work in some way in palliative care following

the experience of watching a close friend and also family members die from cancer and realizing that there was no real support for them. Gathering other interested people: physicians, nurses, social workers, she set out to establish the home care service in 1984 and also in 1993 to set up the Israel Association of Palliative Care, of which she was the first chair, retiring in 2002:

“In order to build the organization I went to the library, I looked for all the research on palliative care. By training I am a sociologist/anthropologist and then I went into gerontology and so today I call myself a gerontologist. OK? And I’m used to doing research because that’s what we do. There were four or five books altogether on hospice at the time, or anything to do with hospice, and there were journal articles. An important book for me described how these people wanted to introduce palliative care into their hospital in the United States. They made this wonderful plan to change the whole hospital and put palliative care in every department. They worked for a year but in the planning they had not included the people who were supposed to use the service, and they were completely ignored and thrown out of the departments. Well that told me something. It meant that everything we did, every step of the way, we had to explain to the people who would have to provide services and include in the planned provision. The initial reaction of local physicians, the Ministry of Health and the Ministry of Social Services was that we were slightly mad; palliative care was neither medicine nor social services. However we were very persuasive.

“I’m always talking in the plural for the very simple reason that we were four or five people who did this work consistently. We added a young psychiatrist; we thought the psychiatrist would be for the patients, in the end he was actually for the team. Because for all of us this was something new, dealing with death, immediate death, how do we handle it? ...I’m not a physician, I’m not a social worker, I’m not a nurse, and I’m not any of the direct disciplines of palliative care. I always was in the position of learning the material. What I would do is I’d learn it, and I’d ask the nurse or physician, ‘Would you say this was this way?’ and they would correct me, ‘Would you say this was that way?’ So it turned out that I could develop a general plan for developing training programs and palliative care services in Israel. I wasn’t being paid by anyone. OK? So that was my great advantage, that I could say exactly what I think and without anyone feeling attacked or competing or anything of that sort, and very long time ago I learned anything that had to do with a patient, I just put aside my ego.”

**Dr. Netta Bentur, sociologist, Academic Health Research, Myers–JDC, Brookdale Institute, Jerusalem:** interviewed by Amanda Bingley, 3 May 2005. Length of interview: 1 hour 4 minutes

Netta Bentur talks about her work in academic health research and how she has specialized in research in palliative care: mapping services and exploring patient and caregiver experiences of care, pain relief and symptom control. She co-authored a report on service provision in Israel in 2004, which included looking at different models and systems by which palliative care is provided.

**Miryam Morganstern, homeopath and trainee spiritual counselor, Cancer Pain and Palliative Medicine Service, Sha'are Zedek Medical Center, Jerusalem:** interviewed by Amanda Bingley, 7 May 2005. Length of interview: 1 hour 10 minutes

Miryam Morganstern is currently training in spiritual counseling. She talks about her background in education and psychology, going on to train and for the last 13 years to practice as a professional homeopath. She discusses how important palliative care work is for her, and the extraordinary lessons in compassion she has learned in the course of her professional work as a homeopath emphasized in her current work as a trainee spiritual counselor at Sha'are Zedek.

**Dr. Shlomith Perry, social worker, Beilinson Oncology Unit, Rabin Medical Center, Tel Aviv, Head of the Psycho-Oncology Society, Israel:** interviewed by Amanda Bingley, 1 May 2005. Length of interview: 55 minutes

Shlomith Perry talks about her supportive and palliative care work as a social worker with patients in the oncology unit. She completed her doctorate in genetic counseling for women with breast cancer and has a particular interest in work which addresses these kinds of ethical dilemmas for cancer patients, especially those patients who have a poor prognosis:

“At the beginning, I thought that we should stop all the DNA testing.

At the end, I've realized that people can manage it, and we have to be with them all the way and they can decide very good decisions, but the medical system has to be with them, not to make the tests and go back, but to be involved in the decision. So after I finished the Ph.D. we opened clinics for high-risk women, this was the fruit of my Ph.D. We opened [clinics] here in the hospital for follow-up.”

She explains that her work in palliative care is due to increase as the new Davidoff Center opens and they plan to have a dedicated palliative care consultant and team. She is head of the psycho-oncology society in Israel and actively involved in developing support for children at the end of life and their bereaved parents, and also in encouraging psycho-social support and education for patients.

**Professor Michael Silbermann, Director of the Middle East Cancer Consortium (MECC):** interviewed by Amanda Bingley at Haifa, Israel, 10 May 2005. Length of interview: 1 hour 3 minutes

Professor Silbermann talks about his role in developing the work of MECC and the original aims and objectives of the organization to promote a standardized cancer registry in member countries in order to develop effective cancer control programs. He describes how, since 2004, MECC has started to address the palliative care needs in member countries, funding health professionals to attend training seminars and setting up “train the trainer” courses nationally and internationally. Professor Silbermann explains that he is a surgeon and served as the Chief Scientist for the Ministry of Health in Israel. He talks about his own increasing interest in palliative care, and his involvement at the Italian Hospital, Haifa which has developed a palliative care service and runs a hospital-based unit, where the patient is cared for physically and emotionally:

“What impresses me most there is really the attitude of the staff—most of them are nursing sisters, nuns—to the patient; that is just amazing. I'm so impressed, you know, they sit with the patients on their own initiative, the patient doesn't have to ring and ring and ‘Please come and do...’—they come and they say ‘How are you doing? Can we do something for you?’ I mean, many of the cancer patients, many are lonely, so being alone and being a patient that is close to death, that's a very, very unpleasant situation. So if somebody bothers to come and sit with you and puts his hand on you and asks ‘How are you feeling today? Can I do something for you?’ and this...this is I think a big, big thing. And I was there and I visit there quite often, just to see what's going on. And I think this will be one of the topics that we are going to really emphasize...and palliative care would eventually become one of the very most important issues that MECC will be involved in.”

*Professor Abraham Steinberg, Center for Medical Ethics, The Hebrew University-Hadassah Medical School, Jerusalem: interviewed by Amanda Bingley, 4 May 2005. Length of interview: 47 minutes*

Rabbi Steinberg discusses his work in medical ethics as chair of the Steinberg Committee which debated the formulation of a law for the dying patient for which legislation was passed in December 2005. The law addresses end-of-life issues, including instituting statutory provision of palliative care, and legislation on euthanasia and assisted suicide. He describes the political, religious, medical and humanitarian aspects of the debate and concludes that the law must adhere to moral principles, and although this may not be perfect for everyone, for example those in extreme, intractable situations, the important point is that the law proves workable and acceptable for the greatest number of people.

## REFERENCES

- Azoulay D, Brajtman S, Yehezkel M, Shahal-Gassner R, Cohen A. When the family demands the discontinuation of morphine, *European Journal of Palliative Care*, 2000;7:4,138-140.
- Anson J & Anson O. Death rests a while: holy day and Sabbath effects on Jewish mortality in Israel, *Social Science and Medicine*, 2001;52:83-97.
- Carmel S, Mutran E. Wishes regarding the use of life-sustaining treatments among elderly persons in Israel: an explanatory model, *Social Science & Medicine*, 1997;45:1715-1727.
- Cherny NI. Israel, status of cancer pain and palliative care, *Journal of Pain and Symptom Management* 1996;12:116-117.
- Cohen MZ, Musgrave CF, McGuire DB, Strumpf NE, Munsell MF, Mendoza TR, Gips M. The cancer pain experience of Israeli adults 65 years and older: the influence of pain interference, symptom severity and knowledge and attitudes on pain and pain control, *Supportive Care in Cancer*, 2005;13:708-714.
- Cooper-Kazaz R, Friedlander Y, Steinberg A, Sonnenblick M. Longitudinal changes in attitudes of offspring concerning life-sustaining measures for their terminally ill parents, *Journal of the American Geriatric Society*, 1999;47:1337-1341.
- Freedman LS, Barchana M, Al-Kayed S, Qasem MB, Young JL, Edwards BK, Ries LAG, Roffers S, Harford J, Silbermann M. A comparison of population-based cancer incidence rates in Israel and Jordan. *European Journal of Cancer Prevention* 2003;12:359-365.
- Livneh J, Garber A, Shaevich E. Assessment and documentation of pain in oncology patients, *International Journal of Palliative Nursing* 1998;4:169-175.
- Levin, M. *It takes a dream: the story of Hadassah*, Jerusalem: The Women's Zionist Organization of America, 1997.

- Loven, D., Goldberg, E., Hart, Y. & Klein, B. (1990) Place of death of cancer patients in Israel: the experience of a 'home-care programme,' *Palliative Medicine* 1990;4:299-304.
- Musgrave, C. Rituals of death and dying in Israeli Jewish culture, *European Journal of Palliative Care* 1995;2:2,83-86.
- Rosen B, Goldwag R. In: Thomson S & Mossialos E, eds. *Health Care Systems in Transition: Israel*, Copenhagen: European Observatory on Health Care Systems, 2003;5:1.
- Singer, Y. and Shvartzman, P. (1998) The feasibility and advisability of administering home blood transfusions to the terminally ill patient, *Journal of Palliative Care* 1998;14:46-48.
- Sonnenblick M, Gratch L, Raveh D, Steinberg A, Yinnon AM. Epidemiology of decision on life-sustaining treatment in the general internal medicine division, *Harefuah*, 2003;142:650-653, 720.
- Steinberg A. End of life decision-making process, *Harefuah*, 2003;142:672-673, 718.
- Stjernsward J, Clark D. Palliative medicine – a global perspective. In: Doyle D, Hanks G, Cherny N, and Calman K, eds. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 2003.
- Waller, A. Hospice and palliative care services in Israel. In Saunders, DC and Kastenbaum R. *Hospice care on the international scene*. New York: Springer Publishing, 1997, pp. 235-241.
- [www.who.int/cancer/palliative/en](http://www.who.int/cancer/palliative/en).

## ENDNOTES

1. World Factbook: [www.cia.gov/publications/factbook/geosis.html](http://www.cia.gov/publications/factbook/geosis.html).
2. World Factbook July 2004 est. [www.cia.gov/publications/factbook/geosis.html](http://www.cia.gov/publications/factbook/geosis.html). In August 2005, the Israeli government withdrew its settlers from the Gaza Strip.
3. For history and discussion see Rennert G. Considerations in planning a national cancer control program – the case of Israel, *Public Health Review*, 1990-1991:18:117-128.
4. Israel's National Cancer Control Program (NCCP) policy guidelines follow WHO recommendations. See WHO (2002) *National Cancer Control Programmes: policies and managerial guidelines*, World Health Organization: Geneva. [www.who.int/cancer/media/en/408.pdf](http://www.who.int/cancer/media/en/408.pdf).
5. For example of early discussion of developing AIDS policy see: Ben-Ishai Z. National AIDS Policy of Israel, In I. Schenker et al. (eds.) *AIDS Education*, New York: Plenum Press, 1996, pp. 81-85.
6. Robinson, E. (2002) The Israel National Cancer Control Program. [www.asco.org/ac](http://www.asco.org/ac).
7. IOELC interview: Dr. Alexander Waller -Tel Hashomer - 7 May 2005.
8. Waller A. (1997) 'Hospice and palliative care services in Israel,' In Dame C. Saunders and R. Kastenbaum, *Hospice care on the international scene*. New York: Springer Publishing, 1997, pp. 235-241.

9. IOELC interview: Dr. Michaela Bercovitch - Tel Hashomer – 1 May 2005.
10. IOELC interview: Ruth Gassner, Dr. Azoulay Daniel, Malka Yehezkel, Helen Englesberg and Judy Yoran – 4 May 2005.
11. IOELC questionnaire: Ruth Gassner – 8 March 2005.
12. Levin M. *It takes a dream: the story of Hadassah*, Jerusalem: The Women's Zionist Organization of America, 1997.
13. IOELC interview: Dr. Nathan Cherny - Sha'are Zedek – 4 May 2005.
14. IOELC interview: Jonathan Rudnick – Sha'are Zedek – 4 May 2005.
15. IOELC interview: Dr. Yoram Singer – Negev Palliative Care Services - 5 May 2005.
16. IOELC interview: Professor Pesach Shvartzman, Negev Palliative Care Services - 5 May 2005.
17. Delbar V. (1999) From the desert: transcultural aspects of cancer nursing care in Israel, *Cancer Nursing* 1999;22:45-51.
18. Beersheba – hospitals information: Soroka Medical Center; [www.soroka.org](http://www.soroka.org). This is the site of the medical school for Ben-Gurion University of the Negev, Faculty of Health Sciences.
19. Shibli J, Oberman A, Szlaifer M. a) *Dying, death and bereavement: rituals of Islam* b) *End of life ethics in Islam*, Poster presentations EAPC 2003 The Hague.
20. Nechustan G, Oberman A, Szlaifer M. a) *A volunteer? Yes, but only a good one* b) *Is volunteer pre-selection process required?* Poster presentations EAPC 2003 The Hague
21. Szlaifer M. *Making a difference: palliative care in Israel* Presentation at the Cancer Nursing conference, Wembley, London, UK, 2002.
22. IOELC interview: Mali Szlaifer – Nazareth - 8 May 2005
23. Clalit Health Services (Kupat Holim Clalit) was one of the original, and largest, nongovernmental, not-for-profit, voluntary health plan insurance schemes. A health plan insurer is also referred to generically as a Health Maintenance Organization (HMO). Clalit used to be known as the General Sick Fund or “Kupat Holim” (which literally translates as “health plan”).
24. IOELC interview: Dr. Jeremy Jacobs, Dr. Ora Rosengarten, Yonat Lamed, Timna Zistling, Jerusalem Home Hospital – 3 May 2005.
25. Brandon N. (1999) The hospice volunteer *Support: Bulletin of the Israel Association of Palliative Care* 1999;12. (See also IOELC interview: Dr. Ora Cibulski, - 13 May 2005.)
26. French Hospital, St. Louis Mission, information posted Rev R. Adam Forno. [www.al-bushra.org/Truth/living.htm](http://www.al-bushra.org/Truth/living.htm) 26 June 1997.
27. IOELC questionnaire and email communication: Kassim Baddarni – 21 September 2005.
28. IOELC interview: Professor Michael Silbermann, Executive Director MECC – Haifa - 10 May 2005.
29. The Embassy of Italy *Italy in Israel* – Special Issue, June 2 2005 [www.ambtelaviv.esteri.it/NR/rdonlyres](http://www.ambtelaviv.esteri.it/NR/rdonlyres).
30. IOELC Field notes: conversation with Reiki healer - 8 May 2005.
31. Information provided by Dr. Amitai Oberman – 21 July 2005.
32. IOELC interview: Dr. Shlomith Perry, psycho-oncologist, Beilinson Oncology Unit, Rabin Medical Center, Tel Aviv – 1 May 2005.
33. IOELC interview: Dr. Netta Bentur – 3 May 2005. See also Bentur N. & Resnitsky S. *An Overview of Palliative Care Services in Israel*, presentation from Myers-JDC, Brookdale Institute, Jerusalem, 2004.
34. IOELC interview: Aliza Yaffe, Head Nurse, Israeli Cancer Association – 13 May 2005.
35. For more details of the history of the Israeli health system see Rosen et al. (2003).
36. Rosen B, Goldwag R in Thomson S & Mossialos E, eds. *Health Care Systems in Transition: Israel*, Copenhagen: European Observatory on Health Care Systems, 2003;5.
37. IOELC interview: Dr. Jim Shalom, Dr. Eyal Goldberger, Yael Bleich and Yaniv Ben-Shoshan, HUG – 9 May 2005.
38. IOELC interviews: Dr. Michaela Bercovitch at Tel Hashomer – 1 May 2005; Dr. Jeremy Jacobs, Jerusalem Home Hospital – 3 May 2005; Dr. Yoram Singer, Negev Palliative Care Services – 5 May 2005; Mali Szlaifer, Milton & Lois Shiffman Home Hospice of the Valleys – 9 May 2005
39. IOELC interviews: Ruth Gassner, Ina & Jack Kay Hospice – 4 May 2005; Dr. Yoram Singer, Negev Palliative Care Services – 5 May 2005; Dr. Jim Shalom, HUG – 9 May 2005
40. IOELC interview: Dr. Nathan Cherny, Sha'are Zedek, Jerusalem – 4 May 2005; Dr. Amitai Oberman, Home Hospice in the Valleys, Nazareth – 10 May 2005.
41. IOELC interviews: Dr. Yoram Singer, Negev Palliative Care Services – 5 May 2005; IOELC interview: Ruth Gassner, Dr. Azoulay Daniel, Malka Yehezkel, Helen Englesberg and Judy Yoran – 4 May 2005.
42. IOELC interview: Dr. Amitai Oberman, Home Hospice in the Valleys, Nazareth – 10 May 2005.
43. See for example Azoulay et al. for discussion of the dilemmas faced by palliative care teams when there is conflict between the team and the patient's family about opioid prescriptions: Azoulay, D., Brajtman, S., Yehezkel, M., Shahal-Gassner, R., Cohen, A. When the family demands the discontinuation of morphine, *European Journal of Palliative Care*, 2000;7:138-140.
44. Dr. Jim Shalom in IOELC interview: Dr. Jim Shalom, Dr. Eyal Goldberger, Yael Bleich and Yaniv Ben-Shoshan, HUG – 9 May 2005.
45. Population figures [www.citypopulation.de/Israel.html](http://www.citypopulation.de/Israel.html).
46. IOELC interview: Dr. Ilene Ora Cibulski, Home Care Hospice of Kiryat Tivon – 13 May 2005.
47. [www1.haifa.muni.il/spru/doc/YB/Dmgrp/Y2003/Download/DemographyDL.pdf](http://www1.haifa.muni.il/spru/doc/YB/Dmgrp/Y2003/Download/DemographyDL.pdf).

48. IOELC interview: Dr. Netta Bentur – 3 May 2005. See also Bentur N & Resnitsky S. *An Overview of Palliative Care Services in Israel*, presentation from Myers-JDC, Brookdale Institute, 2004.
49. IOELC interview: Dr. Alexander Waller, Tel Hashomer, Tel Aviv – 8 May 2005. See also Waller A, Hospice and palliative care services in Israel. In Saunders, DC. and Kastenbaum R. *Hospice care on the international scene*. New York: Springer Publishing, 1997, pp.235-241.
50. IOELC interview: Shulamith Werner, physiotherapist Tel Hashomer, Tel Aviv – 1 May 2005.
51. Cibulski, O. Israel Association of Palliative Care Definitions and Objectives *Support: Bulletin of the Israel Association of Palliative Care* 1999;12. (See also IOELC interview: Mali Szlaifer - 8 May 2005.)
52. Email communication Amitai Oberman and Mali Szlaifer, Home Hospice of the Valleys, Nazareth - 10 November 2005.
53. Israel Cancer Association web page [www.cancer.org.il](http://www.cancer.org.il).
54. IAPHC website [www.hospicecare.com/yp/](http://www.hospicecare.com/yp/).
55. Dr. Nathan Cherny: discussion at the MECC meeting 2-3 February 2004, Larnaca Cyprus.
56. Singer Y & Shvartzman P. The feasibility and advisability of administering home blood transfusions to the terminally ill patient, *Journal of Palliative Care* 1998;14:46-48.
57. The Middle East Cancer Consortium (MECC) was established in 1996 with the aim of setting up population-based cancer registries for member countries in order to monitor cancer incidence, mortality and epidemiology, promote preventative health policy and encourage research and educational links. (See also Silbermann M. Perspectives for cancer epidemiology research in the Middle East *Gastrointestinal Oncology*, 2001;4,181-181.)
58. See for example sociological study by Rubin S, Malkinson R, Witztum E. Trauma and bereavement: conceptual and clinical issues revolving around relationships, *Death Studies* 2003;27:667 – 690. Also for clinical/sociological research studies see Loven D, Goldberg E, Hart Y, Klein B. Place of death of cancer patients in Israel: the experience of a 'home-care programme,' *Palliative Medicine* 4, 1990;299–304. Yaniv H. Sexuality of cancer patients: a palliative approach, *European Journal of Palliative Care*, 1995;2:69-72.
59. Cherny, NI. The problem of suffering. In Doyle D, Hanks G, Cherny N, Calman K. (eds.) *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 2003, pp. 7-14. Cherny NI. Israel, status of cancer pain and palliative care. *Journal of Pain and Symptom Management* 1996;12:116-117. Also see extensive references listed on the Research website for the *Cancer Pain and Palliative Medicine Unit, Sha'are Zedek Hospital, Jerusalem* [www.szm.org.il](http://www.szm.org.il).
60. Bercovitch M, Waller A. Transcutaneous electrical nerve stimulation (TENS). In Doyle D, Hanks G, Cherny N, Calman K. (eds.) *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 2003, pp. 405-410.
61. Waller A. Enigma of terminal dehydration, *American Journal of Hospice and Palliative Care* 1999;16:442.
62. Bercovitch M & Adunsky A. Patterns of high-dose morphine use in a home-care hospice service: should we be afraid of it? *Cancer* 2004;101:1473–7.
63. Bercovitch M, Waller A, Adunsky A. High dose morphine use in the hospice setting: A database survey of patient characteristics and effect on life expectancy, *Cancer* 1996;86:871–7.
64. Livneh J, Garber A, Shaevich E. Assessment and documentation of pain in oncology patients, *International Journal of Palliative Nursing* 1998;4:169-175. Sapir R, Catane R, Strauss-Liviatan N, Cherny NI. Cancer pain: knowledge and attitudes of physicians in Israel, *Journal of pain and symptom management*, 1999;17:266-272.
65. Delbar V. From the desert: transcultural aspects of cancer nursing care in Israel, *Cancer Nursing*, 1999;22:45-51.
66. See Shibli J, Oberman A, Szlaifer M. a) *Dying, death and bereavement: rituals of Islam* b) *End of life ethics in Islam* Poster presentations EAPC 2003 The Hague.
67. Gilbar I. Length of cancer patients' stay at a hospice: does it affect psychological adjustment to the loss of the spouse, *Journal of Palliative Care*, 1999;14:16-20.
68. Kapp MB Living and dying in the Jewish way: secular rights and religious duties, *Death Studies*, 1993;17:267-276.
69. Sonnenblick M. Advanced medical directives, *Harefuah* 2002;141:181-188. Also see Gross M, Treating competent patients by force: the limits and lessons of Israel's Patient's Rights Act, *Journal of Medical Ethics*, 2002. [www.jmedethics.com](http://www.jmedethics.com).
70. IOELC interview: Professor Abraham Steinberg, Sha'are Zedek Medical Center, Jerusalem – 4 May 2005.
71. Azoulay D, Brajtman S, Yehezkel M, Shahal-Gassner R, Cohen A. When the family demands the discontinuation of morphine, *European Journal of Palliative Care*, 2000;7:138-140.
72. Waller, A. Hospice and palliative care services in Israel. In Saunders DC, & Kastenbaum R. *Hospice care on the international scene*. New York: Springer Publishing, 1997, pp. 235-241. IOELC interview: Dr. Alexander Waller, Tel Hashomer, Tel Aviv – 8 May 2005. IOELC interview: Dr. Michaela Bercovitch, Tel Hashomer, Tel Aviv – 1 May 2005.
73. IOELC interview: Tamie Goan, hospice home care nurse, Tel Hashomer, Tel Aviv – 1 May 2005.
74. Ruth Gassner in IOELC interview: Ruth Gassner, Dr. Azoulay Daniel, Malka Yehezkel, Helen Englesberg and Judy Yoran, Hadassah, Mt. Scopus – 4 May 2005.
75. Malka Yehezkel in IOELC interview: Ruth Gassner, Dr. Azoulay Daniel, Malka Yehezkel, Helen Englesberg and Judy Yoran, Hadassah, Mt. Scopus – 4 May 2005.
76. IOELC interview: Sarah Rimer, social worker, Tel Hashomer, Tel Aviv – 1 May 2005.
77. Musgrave, C. "Rituals of death and dying in Israeli Jewish culture," *European Journal of Palliative Care* 1995;2:83-86.

78. Ruth Gassner in IOELC interview: Ruth Gassner, Dr. Azoulay Daniel, Malka Yehezkel, Helen Englesberg and Judy Yoran, Hadassah, Mt. Scopus – 4 May 2005.
79. Email communication: Dr. Amitai Oberman – 18 August 2005.
80. Email communication: Kassim Baddarni – 9 January 2008.

# Chapter 7

## Palliative Care in Jordan

Jordan (population 5,329,000) (1) is a country in the Middle East northwest of Saudi Arabia. It covers an area of 92,300 square kilometers. Mostly landlocked (apart from 26 km bordering the Gulf of Aqaba), its boundaries border Iraq, Israel, Saudi Arabia, Syria, and the Palestinian West Bank.

### PALLIATIVE CARE SERVICE PROVISION

#### Current services

In Jordan, four palliative care services are offered by two organizations: the Al Malath Foundation for Humanistic Care and the King Hussein Cancer Center. Supportive care is offered at Al Basheer Hospital (Table 7.1).

These services are based in the capital city, Amman, and include a home hospice team for adults and children, a hospital and home hospice team for adults, and hospital-

based supportive care for adults. Pain and symptom relief for cancer patients is also provided in some oncology units in other general hospitals in Amman and Irbid.

The Al Malath Foundation for Humanistic Care runs one service in Amman: the home hospice team Al Malath Hospice. The team supports four volunteer nurses who work alone, on their own schedule, in other areas of Jordan. Since 1994 (the year following the establishment of the hospice) admissions have averaged around 30-40 patients per year (Table 7.2).

In 2004, around 63% of patients admitted to the home hospice were supported to die in their own home. Some families request that their relative be admitted to hospital in the 24 hours before death, and 20-30% of home hospice patients die in hospital having been admitted weeks or some days prior to death.

The majority of patients have cancer, but the hospice will occasionally care for patients with other illnesses at the end of life. In the early years, nurses were most likely to refer to the hospice. Increasingly physicians are encouraged to refer patients (2). A proportion of patients are self-referring, through family or friends.

The hospice provides a 24-hour on-call service and the home care team will continue to support their patients if requested after admission to hospital. The Foundation has an equipment loan service providing, for example, hospital beds, wheelchairs, bathing and toilet aids, and oxygen cylinders free of charge, with an option to make a donation. Financial help is offered from a special fund in cases of hardship and there is also a “special last wishes” fund which can provide for a personal request by the patient towards the end of their life. Examples include funding the cost of a special trip, and the making of a commemorative video of the patient for their children.

The King Hussein Cancer Center (KHCC) is a government hospital dedicated to treatment of adults and children with cancer. Patients are referred for treatment from



Table 7.1 Palliative care provision in Jordan 2005

Adult and Pediatric* Services							
	Freestanding unit	Hospital unit	Hospital support team	Home care	Day care	Clinic/Drop-in center	Grand Total
Al Malath Foundation *				1			1
King Hussein Cancer Center			1	1			2
Al Basheer Hospital			1				1
<b>Total</b>			<b>2</b>				<b>4</b>

all over Jordan. Since October 2004, the hospital has offered two key palliative care services—hospital support and home care for adults with cancer—delivered by the multi-professional hospice team including director, physicians, nurses, psychologists, physiotherapist, social worker and nutritionist. The team cares for patients in the following settings:

patients admitted onto the wards;

patients attending the outpatients department;

patients at home if they reside in the western areas of Amman within a 6 km range of the hospital.

Telephone support is available for KHCC patients and their families living in other areas of the country. There are plans to extend home care services into other areas of the country via the recently reformed community health

Table 7.2 Al Malath Foundation – change in admissions and home visits over years 1994, 2000, 2004

	1994	2000	2004
Hospice home care admissions	11	34	43
Home visits	120	782	576

Source: Al Malath Foundation annual statistics – with kind permission Rana Hammad, Director: Al Malath, May 2005

care system. An eight-bed inpatient unit at KHCC was opened in 2005 (Table 7.3).

Referrals are made by either the patient's primary physician or via the oncology unit based at KHCC (3). The criterion for admission—for either palliative support at hospital or hospice care at home—is based on the patient's decision about resuscitation:

“Do not resuscitate” (DNR): Home care palliative services are offered to all those patients at the end of life who have decided they do not want resuscitation, even if they are re-admitted to hospital.

“Resuscitate” (non-DNR): Palliative support is offered to patients at the end of life who choose to stay in hospital and in spite of a poor prognosis wish to be resuscitated, for example, in the event of sudden collapse.

In May 2005, there were six patients in home care (DNR) and 10 being offered hospital palliative support (non DNR). Around 17-20 patients are admitted to the palliative care service per month; it has a capacity to admit 30 patients per month (4).

### *Hospital oncology units*

There are three major oncology units in government-funded hospitals in Amman, which offer pain and symptom relief

**Table 7.3 Key palliative care services in development, and currently offered by the home hospice team to King Hussein Cancer Center patients**

Current service (report 2005)	Service in development
Hospital-based ‘Palliative Support Service’ (adults) ~ inpatient ~ outpatient	KHCC-based 8-bed inpatient hospice unit
Home care support (adults) ~ home visits in Amman ~ telephone support in other areas of Jordan	Community-based home care throughout Jordan
	Pediatric palliative care

to cancer patients at the end of life. Civilian patients can access supportive care, and, since 2004, specialist pain and symptom management in the oncology unit at the government Al Basheer Hospital. The Jordan University Hospital offers pain and symptom relief. Army patients can access relief through the Royal Medical Services at the military hospital King Hussein Medical Center. Other hospitals able to provide pain and symptom relief at end of life include:

In Amman: the Islamic Hospital (run by the Islamic Center Charity Society) (5); the privately funded Speciality Hospital;

In Irbid, the King Abdullah University Hospital (KAUH) and (by referral) from KAUH at the Health Center of Jordan University of Science and Technology (JUST).

These units and hospitals are part of the Jordan Pain Relief and Palliative Care Initiative, which is supported by the World Health Organization (WHO) and the Center for Palliative Care Studies at San Diego Hospice, California, USA (6).

Patients may ask to be referred or may self-refer to the specialist palliative care services at Al Malath or KHCC. Patients at the end of life residing outside Amman, who have left the major oncology units to return to their homes, can access basic pain and symptom relief either from their primary physician or in local hospitals.

There are no reports of any government-funded specific palliative care services for patients at the end of life with other illnesses, including HIV/AIDS. There are plans by government to provide insurance for patients to receive end-of-life care if they have neurological illnesses, such as Alzheimer’s disease. As of 2005 patients and their families pay private nursing agencies to provide “aid nurses” for patients with other illnesses at the end of life.

### *Reimbursement and funding for services*

Patients needing palliative care in Jordan can access free services from the charitable non-governmental organization (NGO) Al Malath Foundation if they live in Amman or have access to one of the four volunteer Al Malath nurses in their locality. Al Malath Hospice receives a small payment of up to 1000 Jordanian Dinar (JD) (7) per year from the General Union, the Philanthropic Societies, and the Ministry of Social Development. Al Malath offers all services, including equipment, free of charge. There are plans to institute a “sliding scale” of fees, but care will continue to be free to all those who cannot afford to pay (8).

King Hussein Cancer Center is an NGO providing services to patients either with government-subsidized insurance or for private fees. Since 2004, the government provides subsidized services for all cancer patients if they are Jordanian citizens. Patients with cancer can join the government Royal Court insurance scheme (regardless of previous health insurance status), and—providing they renew their insurance at six monthly intervals—need only pay a minimum of 10% of all health care fees. Private sector insurance, which provides coverage for around 59% of the population, does not include palliative care services (9).

All cancer patients have to pay for their medications. However, they can choose either to obtain a 90% discount on prescriptions through Royal Court insurance (dispensed via pharmacies at KHCC or Al Basheer Hospital) or to have the prescriptions dispensed through a private pharmacy and pay the full cost. Since 2004, new government legislation allows all children under five to be entitled to free health care (10).

### *Opioid availability and consumption*

The International Narcotics Control Board (11,12) has published the following figures for the annual consumption

of narcotic drugs in Jordan: codeine 35 kg (down from 79 kg in 1998); morphine 3 kg (up from 1 kg in 1999); pethidine 24 kg (up from 17 kg in 1998).

For the years 2000-2002, the average defined daily dose consumption of morphine for statistical purposes (S-DDD) (13) in Jordan was 11 (14). Opioids and other related medications are available in Jordan, although the range of suitable preparations can be limited.

Since 2003, the Ministry of Health has been developing a National Palliative Care Programme with the support of WHO. An important aspect of the program is to facilitate appropriate policy on opioid prescription.

Dr. Jan Stjernswärd of WHO writes: “The Jordan Pain Relief and Palliative Care Initiative (JPRPCI) is a World Health Organization (WHO) Demonstration Project for the Middle East Region. Following negotiations with the Ministry of Health (MOH) and WHO, a public health approach was established, introducing the WHO foundation measures of education, drug availability and supporting policies. In August 2003, a MOH/WHO workshop was attended by leading national policy makers and clinicians who agreed to establish a National Programme Initiative. Dr. Samir Khleif, Director of King Hussein Cancer Center, has since been addressing policies, drug availability and educational issues. Already there have been changes in opioid prescribing policies and nationally produced, inexpensive generic immediate release morphine and slow release morphine tablets are about to come on the market, with a policy that over 80 per cent of the estimated increase in morphine use will be covered by these drugs.” (15)

Dr. Bassam Hijawi, Director of Health Promotion and Protection in the Ministry of Health explains that, as of May 2005, improved legislation on opioid production and prescription policy is imminent, although there are still some issues to be resolved: “We face a problem of legislation, prescription [and production] of drugs. Sometimes the manufacturers of the drugs are asked for a big amount of morphine, and they say that it is costly... more than 20,000 JD and we cannot supply this amount. So [the supply] expires and nobody [can] use it. Sometimes the hospitals ask for extra amounts, and nobody knows the exact amount. So the system is sometimes [a problem]. I hope now we are on the correct way and that we are now at the end [ready] to sign [and complete the policy]. His Excellency the Minister of Health [has] said, ‘I am ready to send these issues to parliament to change, to update the legislation that is suitable for our current position.’” (10)

Since the early 1990s, at the inception of the first palliative care service, difficulties around the provision of opioids, and the different modes of prescription that are suitable in palliative care, have been eased with support from the Royal Court, which recognized the specialized needs. For instance, as Rana Hammad, Director of Al Malath, explains: ‘We have three morphine pumps now and they are the only three in Jordan. We’ve changed the regulations when it comes to narcotics. We were fortunate that Crown Prince Hassan, at that time [in the early 1990s] helped us with one phone call. It became easier and we started having more ampoules, more pills, and for three years we managed to get the immediate release [morphine]. The first time I took the pump to Al Basheer Hospital, which was the Center for giving the morphine to patients, and I said, ‘I want 100 ampoule,’ and they said, ‘What!?’ I said, ‘Okay, 50, and they said maximum five.’ So ‘but five cannot prime the [pump].’ So it changed--it changed quickly.” (16)

However, since the government committee on opioid regulations has been facilitating the policy on opioids, there is a wider range of opioid preparations available. As Nisreen Al Alfi, a nurse in the KHCC hospice team, describes, the team is now able to use: “... mostly morphine, MST, for pain relief...also adjuncts to medications, like paracetamol, tramadol, dexamethasone. We use fentanyl [transdermal patches] sometimes. We keep them as a last resort, because not all our patients feel comfortable about that and sometimes symptoms of nausea and drowsiness are more prominent with the patches more than the morphine. Sometimes if we have to keep going up, up, up on the morphine, we use a fentanyl patch, or if the patient cannot swallow we might just use the patch as an alternative. Sometimes it won’t work because the patient is really lacking subcutaneous tissue so there’s no absorption, so they’re not going to benefit on the patch.”

Al Malath home hospice also uses MST, and as Rana Hammad explains: “Now we have the immediate release [morphine] that I fought for ten years to get--we have it now. We do the fentanyl patches. We use injectable morphine through the pumps, not through injections. We have also syrups for kids. And we have the weak opioids: tramadol, codeine, all the range of weak opioids we use them...and the non-steroidals for pain. And for nerve pains we use the tricyclic antidepressants, which we introduced--we were the first to use them or to apply them. Of course we have, for symptom management, our regular antifungals, antibiotics, antidiarrheals, all range of normal medications for symptoms. And of course we have the colloids for bedsores, and skin care products.”

WHO reports that from 2004 there has been a demonstrable change in opioid use as a result of the training programs and the change in opioid legislation. For instance, in 2004 KHCC was using 2.7 kg morphine, but by 2005 usage had increased to 4.8 kg morphine. By 2005 Al Basheer Hospital reported increased levels of opioid use, 13,000 mg prescribed as morphine sulphate 10 mg tablets (17).

## PALLIATIVE CARE COVERAGE

Currently there are two organizations offering three specialist palliative care services to adult cancer patients, one of which also admits children and will admit adults with other illnesses at the end of life. These services are based in Amman. Specialist palliative care services are not currently available in any governmental hospitals for adults or children. New services are in process of being developed in Irbid, and in Amman from 2004 as a result of training initiatives in the oncology unit of the government hospital. Two other oncology clinics provide pain and symptom relief to cancer patients at the end of life, all of which are based in the capital city Amman.

As of May 2005, the two organizations offering specialist hospice and palliative care services reported caring for, between them, a total of around 22 patients at any one time, although the total capacity between both organizations is around 45 patients at any time (Table 7.4).

Three oncology clinics provide pain and symptom relief to cancer patients at the end of life, all of which are based in the capital city Amman. Services in other regions of Jordan are limited; the King Hussein Cancer Center (KHCC) hospice team offers telephone support to their patients being cared for at home outside their Amman catchment area. If a patient needs urgent pain or symptom relief, unless or until they can travel back to KHCC the team will advise contacting the family physician or attending a local emergency department. Al Malath Hospice supports four volunteer nurses working independently in other regions outside Amman.

## PALLIATIVE CARE WORKFORCE CAPACITY

### Al Malath Foundation

The home hospice has six full-time team members: a hospice director (a specialist nurse), a physician, and four nurses (of whom two are case managers). The team can call on an additional four part-time members: a pain specialist, a social worker, a dietician, and a religious cleric. Volunteers support the team. Families are supported



**Illustration 7.1: Members of the King Hussein Cancer Center hospice team, Amman, Jordan** [photograph: Amanda Bingley, May 2005].

to give care. Hospice physician Dr. Mazen Al Bashir describes how the caregivers in the family can be taught to manage infusions: “They know exactly whatever it [pump IV infusions] means, what it means when it’s up, when it’s in, and how to check that, and to check the rate; and they know how to use calculator to work out exactly how much to take. Of course, you cannot just put it in and turn your back, you need to make sure they are safe, we have nurses which can supervise this sort of thing and many of the people had nurses there looking after them.” (18)

The case managers are experienced hospice nurses who offer full support for the patient, from nursing procedures, personal care and social needs, including grief therapy for families. They will call on other members of the team as needed; for instance, medical, additional nursing or psycho-social support. The Director of Al Malath, Rana Hammad explains: “[The case manager] has her mobile, if she sees anything she will call me, she will call the physician, we act on things. She will train the family, she will look out for the family, she will deal with the patient, look at possible troubles to come, do all the adjustments at home, check the medications, check the symptoms, check the life signs, and check the body. If she needs a blood test she will order blood tests. She will follow the schedule for changing the dressings or the catheters, or it’s the time to check the hemoglobin or check the potassium. If there is a need, she will arrange with a physician and go with him.”

Table 7.4 Patient activity and capacity in the two dedicated palliative care organizations (May 2005)

Organization	Service	Patient activity	Maximum patient capacity
Al Malath Foundation	home hospice	7	15
KHCC	~ home hospice	6	30 (in both services)
	~ hospital support	10	
<b>Total</b>	<b>3</b>	<b>22</b>	<b>45</b>

### King Hussein Cancer Center

The hospice team has a total of 30 full- and part-time members: a team director, a medical director, a hospice physician, a nurse manager, a home care coordinator nurse, a unit head nurse, a consultation team coordinator, 19 nurses, a psychologist, a social worker, a physiotherapist, a nutritionist, and a team secretary.

The team is supported by other departments at KHCC if the patients or their families request admission for pain and symptom relief. Spiritual counseling is sought from outside clerics at the request of the family. Team members will offer whatever spiritual solace they feel is possible.

The new palliative care training schemes for physicians, nurses and pharmacists have resulted in palliative care knowledge disseminating into the workforce within large oncology units such as at Al Basheer Hospital and also within the new governmental family and community medical centers. In May 2005, there were as yet no records of the capacity of this workforce or the level of care offered.

## NATIONAL AND PROFESSIONAL ORGANIZATIONS

### Al Malath Foundation for Humanistic Care

This organization was founded in 1993 by Rana Hammad, a specialist palliative care nurse. The Foundation is the only non-profit, voluntary NGO in Jordan offering a home care hospice service. The service provides care for adults and children at the end of life who reside in the capital city Amman. Since its inception in 1993, the Foundation has developed a multi-professional home hospice team (Al Malath Hospice) including a physician, nurses, a pain specialist, a social worker, a rehabilitation therapist, and a dietician. Volunteers and religious clergy support the team (19). The home hospice team admits patients:

who live within the “Great Amman Municipality”;

who have life-threatening cancer or poor prognosis of life expectancy due to other illnesses;

who personally (or through their families) ask for palliation and understand the goals of palliative care (physicians or oncologists can refer or patients self-refer); or

who are homebound but have one or two caregivers willing to support them (20).

Since the mid-1990s the Foundation has provided services for an average of 45 patients per year, of which 3-10% have been children and young people under 19 years of age. The home hospice team offers medical and nursing care, psychosocial and spiritual support to patients and their families. An important aspect of the Foundation’s ethos is to offer the option of continuous care and attendance, if requested by the family, in the patient’s last days or hours of life, including accompanying the patient into hospital in the event of the family asking that the patient be admitted.

### King Hussein Cancer Center

The King Hussein Cancer Center (KHCC) was founded in 1997 as the Al-Amal Cancer Center and renamed in 2002 in memory of the late King Hussein. The hospital is a specialized NGO cancer hospital treating adults and children. It has a capacity of 148 beds and currently treats more than 2300 new patients per year. KHCC is the only dedicated cancer center in Jordan. It also attracts 25% of its patients from neighboring countries in the Middle East. The Director, Dr. Samir Khelif, is an oncologist and internationally recognized cancer researcher, who supports palliative care services and has facilitated the development of the KHCC “hospice team.” (21) The KHCC hospice team was established in October 2004, offering palliative care—including medical, nursing, physiotherapy, nutritional, and psychosocial support—in the hospital or at

home to adult patients at the end of life. KHCC is working with WHO to develop a comprehensive palliative care training program and establish a regional training center within the hospital.

### World Health Organization (WHO)

WHO is involved in supporting the development of palliative care services, in particular a review of opioid-prescription policies, and the promotion of education and training. In August 2003, a Ministry of Health/WHO workshop was attended by leading national policy makers and clinicians; they agreed to establish a National Programme Initiative, “The Jordan Pain Relief and Palliative Care Initiative (JPRPCI).” This is a WHO Demonstration Project for the Middle East Region. Negotiations with the Ministry of Health and WHO have resulted in a public health approach being established, introducing the WHO foundation measures of education, drug availability, and supporting policies (22).

### EDUCATION AND TRAINING

Recommendations for palliative care training in Jordan were first proposed—in an unpublished report on assessing need for palliative care for cancer patients in Jordan completed in 1986—by two UK nurses from the charity Macmillan Cancer Support (23). In 1992, concerned health professionals began actively to develop the concept of palliative care services and training in Jordan. Most Jordanian health care professionals, who had completed post-graduate education in the USA or UK, were already aware of the concepts of palliation and end-of-life care. In 1993 the Al Malath Foundation was established, not only to set up the first home hospice service, but also with a commitment to education for people in the community and for health care professionals within Jordan (24).

### Al Malath Foundation

The Al Malath Foundation is committed to both public and professional education. The Director of Al Malath, Rana Hammad, explains: “We serve the community in three ways: patient care is one way, education and training is the other channel we work at. I went round the country giving courses, presentations, panel discussions, from sophisticated conferences down to sitting with lay women on the floor and talking about sadness and grief and the wisdom of God, for example. Also two structured courses at the University for medical students, nursing students, social workers. The third area is support groups and supporting the caregivers in the hospitals. They should be empowered. They should be trained on grief, loss, spiri-

tualities, emotional well-being, understanding, empathy, communication, knowing the value of the work.

“We got a hospice social worker who was a volunteer through the American Peace Corps. She stayed with us for two years, and the first year she got to understand the culture and the needs of the patient, the second year with us we together developed a manual, and she trained the nurses. They trained each other. So they interacted in a way which she knows the needs of those patients and they know the culture. Eventually people will get to know what palliative care is, it is not about skills because it’s there, we can study and we can learn those skills, we can learn how to calculate, we can learn how to assess, but it’s about attitude. So the majority of my training programs are about shaping the attitudes, empowering them, make them understand the value of this work, and then when it comes to knowledge, it’s there.

“I have a one-day program, and I have a two-day program for pain management, and I have a two-week program that I developed for the Ministry of Health; and I have some tailored programs, it depends on the needs, for example, the social workers when they come and they want to talk about the social-psychological emotional aspects of cancer care.”

### World Health Organization (WHO)

The World Health Organization has been actively involved in supporting the development of services and promoting education and training at Al Basheer Hospital and at KHCC. In June 2004, Dr. Jan Stjernswärd of WHO announced:

“All medical and nursing schools are committed to introducing palliative care into their undergraduate education and six palliative care courses, supported by an international faculty and bedside practice, are budgeted for over the coming three years.”

In March 2004, an introductory training course in Amman ran with 32 participants (nine physicians and 23 nurses). In March 2005, introductory and advanced courses ran with 70 participants—physicians, nurses and pharmacists (including two Iraqi doctors), of which 22 participants had returned to complete the advanced course. The advanced group had some class-based training instruction and also did interactive bedside work in small groups discussing cases at two clinical sites, KHCC and Al Basheer Hospital; seeing a large number of patients, initially practicing assessments. In autumn 2005 the course following the training model “Education on Palliative and End of Life Care” (EPEC)—Train the Trainers—ran in collabora-

tion with colleagues from San Diego Hospice and the Hospice of the National Capital Region, USA, and Dr. Stjernswärd (25).

An important aspect of the training was addressing health professionals' opioid phobia by the trainers teaching physicians how to write an opioid prescription, and then witnessing patients improving and wanting to go home. It has proved vital to train pharmacists; for example, Al Basheer pharmacists initially were horrified at the dosages proposed until the improvements in patients' pain and well being was demonstrated. The training includes sessions on specific symptom management, how to disclose prognosis, how to avoid burnout and about other symptom management (e.g. dyspnoea) and withholding fluids and nutrition. The training hospitals and trainers have worked with the religious leaders, who have announced a new fatwa allowing the prescribing of opioids and the appropriate withholding of fluids and nutrition.

### King Hussein Cancer Center (KHCC)

In 2004, the Ministry of Health, supported by WHO and with members of KHCC and other hospitals, formed an education committee. One of the aims of the committee has been to establish a palliative care education and training program for interested health professionals and training for medical and nursing students.

The director of nurse training at KHCC and chairperson of the KHCC training committee, Ahmad Al Khateib, explains that KHCC was designated to be the training Center for palliative care and pain relief in Jordan, and later on to be a regional training Center. KHCC has been chosen because it is the pioneer hospital in the region offering palliative care services and has the facilities and resources to develop these services. KHCC is supported by WHO, which has donated funds to cover courses twice a year. With this collaboration, since March 2004, there have been introductory and advanced training courses at KHCC for physicians, nurses and pharmacists, supported by an international faculty, Dr. Frank Ferris and his team from San Diego Hospice (26). The idea is to help those who have attended the courses from the different institutions to establish palliative care teams in their institutions. Ahmad Al Khateib explains that these courses are expanding: "We have [a] second palliative care training program, conducted in our center; one introductory course for three weeks, and we have around 50 people now on this course who are physicians, pharmacists and nurses, from different institutions [in Jordan]. We have physicians coming from Iraq and the plan is to have physicians from Syria, from Palestine. I hope by this time we might have some of them coming because as I told you the plan was

to become the regional training centre. We have now five international faculty members here at this moment conducting the second part of training course, and the same time an advanced training course. We are going to have a three day workshop starting in March (2006), designed to provide some sort of education for the faculty; the teachers from school of medicine, school of nursing ... helping them to orient about the concept of palliative care and helping them to integrate the concept of palliative care and pain relief in the undergraduate curriculum for school of medicine and school of nursing."

Ahmad echoes the WHO observation that a major difficulty in developing palliative care is the "sensitivity of physicians towards prescribing narcotics... I think that we need to educate the health care providers and to try to change their perception about palliative care and morphine and to understand palliative care."

As part of the development of the training programs, Dr. Amal Bandak, Director of the KHCC hospice team and her colleagues, have compiled a draft manual and guide for training and hospice team development (27).

Since 2004, with the help of Carol El Jabari, director of the NGO Patient's Friends Society based in Jerusalem, KHCC have developed education in the community by establishing a self-help group for women with breast cancer, which provides regular training sessions in preventative and supportive care. There are now around 13 women regularly attending the group at KHCC (28).

### ETHICAL ISSUES

There are three major ethical issues described by palliative care teams in Jordan. The first is the difficulties experienced at the end of life by patients, their families and members of a palliative care team in a medical system that is not yet fully attuned to the concepts of palliative care. Al Malath Medical Director Mazen Al Bashir explains: "There's tension between our [hospice] regime of what needs to be done, or not what needs to be done, but what we want to achieve, and the other medical profession's paradigm. We think of the human being, the whole person and the family, and those guys [oncologists] are really focusing on the size of one of the tumors in the brain for getting the drugs for it. But there's a human being around that tumor. We want to do what we need to do, but they want to give them a drug or give them a shot of chemotherapy, or whatever, or somebody who they record the blood pressure and according to the doctor they are showing liver failure, renal failure, and [the patient] is on a respirator in the ICU studded with metastases everywhere, and they decide to do renal dialysis."

To some extent, it is hoped that this issue will recede as more health professionals—at undergraduate, post-graduate and professional development levels—receive training in the concepts and practice of palliative care, and as there is more public education around end-of-life care.

Closely linked to this ethical dilemma is the second problem that palliative care professionals report: distress in the families at withdrawal of active treatment, including food, drink, and infusions, in the last few days or hours of life. Both organizations, Al Malath and KHCC, found families were best supported by the hospice team ensuring the situation was fully explained and discussed with the caregivers before death became imminent. This discussion with families is a key element of hospice care and includes the general education and support offered to family caregivers throughout the end-of-life period.

Difficulties arise also around a third area--disclosure of diagnosis. Nisreen Al Alfi, nurse at KHCC explains: “I think another problem is problems of disclosure, this is not a problem for all [patients] but we have faced this quite a lot at the beginning. The best thing is if the patient and the family are informed and they decide for themselves. I think with training for the primary physician [in how] to talk about prognosis and so on will make our job easier. The team often can’t do anything with the patients, because we have been faced with rejection sometimes--the patient is angry, ‘I want my primary physician, who are you to tell me, like what I am going to do, why I’m going to die.’ ... there were problems of disclosure and confidence patients have with us.”

However, both organizations report that where the team is sensitive to the needs of patients, families, and their physicians, and where there are more opportunities for training in communication and education of the patient and families, these issues of disclosure and acceptance at the end of life have shown signs of change.

## HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

### Narrative history of palliative care

Interest in palliative care in Jordan was initiated by Crown Prince Hassan in 1985. In 1986, through his office, two nurses from the UK charity Macmillan Cancer Support (then known as Cancer Relief Macmillan Fund) were commissioned to conduct an assessment of palliative care need in cancer patients in Jordan. Their study highlighted the need for pain relief and trained professionals. By 1992

a group of concerned health professionals was discussing how to actively set up palliative care services. Rana Hammad, director of Al Malath Foundation, describes how, with the continuing support of Prince Hassan—who gave Al Malath an award for starting the first service—the hospice was set up in 1993: “I wanted to start an in-patient service because I’m more in control, and because there was no home care, community home care program whatsoever in Jordan. Nothing, not even paid. Nobody goes to homes; all the patients have to go to hospital whatever their conditions. So I thought we will be talking about pain control, we started talking about morphine, and people are about to shoot us because of this. We are talking about empowering patients, quality of life--so we are pioneers in everything. I didn’t want to add another burden of being pioneers also in home care. So I wanted to be in the hospital--the majority wanted home care--and then we had this first phone call from Ann David, who was a lovely British lady, who was our first patient--her husband used to work in the United Nations--and when she became terminal, she decided to die here, at her home here. She said, ‘Why don’t you start and come and visit me.’ So she dragged us, and we started home care. So there has been a sequence of coincidences, of beautiful people who just put us on the right track. It was destined to become, to be.

“A second decision that we had to make: should it be a program under the umbrella of Ministry of Health, or a private sector hospice, or a charity hospice? The toughest way was to be a charity organization, because in Jordan, the charity sector is hard to live in. We don’t have resources or income, so it was hard, but for me it was the most suitable thing because it was the only guarantee to eliminate the human bias when it comes to money. So if I want to deal with people, I’ll deal with them regardless of their ability to pay, regardless of, you know, the income they have or the donations they might give or money they might give. From 1993 till 2004, there was no other program in Jordan.

“It started with primitive resources, but with huge will we’ve got professionals to help us; volunteers. It started from my home, with the space and one huge table as the office for one year; with wheelchairs, my kids playing on both wheelchairs; meetings of the part-time secretary, ‘Come and help me while I cook and do some meeting.’ So I started home care using a taxi from my home. And the first year, we only took one patient, stayed with that patient, helped, tested the needs; saw what the Jordanian people wanted. And modifying, re-modifying again and again, coming back and forth to the basics again; till that patient dies then we take another patient--we haven’t duplicated two patients at the same time. In 1993-1994,

we rented this office, got a car, and added more equipment.”

By 1995 Al Malath had sufficient resources to care for 40 patients – adults and children, over the year. The hospice continues to care for, annually, around this same number of patients.

From the late 1990s WHO began actively to support the development of further palliative care services, encouraged by the establishment of KHCC as a dedicated oncology hospital. Director of nurse training, Ahmad Al Khateib describes the development of the first hospital-based palliative care service:

“August 2003 we started, there was a one day workshop, sponsored by WHO and the Ministry of Health, and KHCC participated in that workshop. One of the outcomes was a recommendation to have a National Palliative Care and Pain Relief Initiative Committee in Jordan, with his Excellency the Minister of Health as chairperson and Dr. Samir Khelif, Director of KHCC, and people who cover all health sectors in Jordan to sit in that committee. Here at King Hussein Cancer Center, two years ago we started the program of palliative care and pain management at home care. I have to say proudly that the only hospital setting palliative care program in Jordan is King Hussein Cancer Center. Now we’re going to have this hospice unit and we are going to extend it for more. And we have the home care program; we have trained nurses and trained physicians to run this service.”

The KHCC team was established in September 2004. Team director Dr. Amal Bandak, with the nurse manager and the team (including two nurses who trained in palliative care with Al-Malath), wrote the guidelines for the inpatient and home care services. The team started with four nurses, but has now expanded to a total of 21 nurses in order to develop small teams able to work within the hospital--in the outpatient department and the new inpatient unit--and in the home care service. The team has a part-time psychologist and is recruiting more psychologists and social workers. Amal Bandak is keen to develop more educational opportunities for the team professionals; in particular she is setting up links with centers in the USA.

At the Faculty of Nursing at Jordan University of Science and Technology (JUST) in Irbid, the largest city in the north of Jordan, Assistant Professor of Nursing, Dr. Suha Omran and her colleagues, are developing palliative care training workshops based at the medical and nursing schools. Currently, the Faculty is offering a unit in oncology nursing for undergraduate nurses included in the

medical surgical course. There is also a Masters program offering a clinical nurse specialist in oncology nursing. The palliative care element is supported by opportunities for student placements at KHCC and Al Malath (29).

## Hospice success stories

### *Al Malath Foundation*

Rana Hammad set up Al Malath in 1993, in response to a need to provide care and comfort to patients at the end of life. For Rana Hammad and hospice Medical Director Mazen Al Bashir, the success of Al Malath lies in the dedication to be totally committed and present for the patient and the family: attending to all aspects of the patient and family needs, medical, personal, social and spiritual. The team supports the patient and family throughout the final stages of life, staying with them through the last hours, however long, and after the patient dies will maintain support for the grieving family, wherever appropriate. Mazen Al Bashir suggests that the vital element of Al Malath is that “We think of the human being, the whole person and the family...”

There is anxiety that the over-medicalization of end-of-life care results in a loss of the holistic and humane approach, felt so essential by Al Malath. Thus, the team encourages the newer developing services to hold to the compassionate element of palliative care.

### *King Hussein Cancer Center*

A combination of support from the existing expertise of Al Malath and WHO, together with the determination to develop a wide coverage of services, is proving successful in setting up several teams at KHCC. The Director of Nursing Education, Ahmad Al Khateib, is dedicated in his resolve to create a regional training center and encourage a wide uptake across Jordan, and the region, of the concepts and practice of palliative care.

## LIFE/ORAL HISTORIES

*Rana Hamad—Director: Al Malath Foundation for Humanistic Care, Amman: interviewed by Amanda Bingley, 12 May 2005--duration of interview: 76 minutes.*

Rana Hammad talks about her early work in nursing and completing a Master’s in Nursing Research and her growing interest in caring for patients at the end of life. She describes how she was alerted to the need for palliative

care in Jordan by a TV appeal about cancer research. She explains:

“When we started, we started on October 12th, 1992, there had been a telethon on TV, to raise funds for the King Hussein Cancer Center--at that time it was called the Amal Cancer Center and Amal in Arabic means hope, so it is the center for hope for cancer cure, and it was the first of its kind and I think it was the first, and the whole country were so enthusiastic to do something about cancer... When they started repeating the hope center for cancer cure--it was repeated for millions of times--it started hitting me. The majority of cases--eight out of ten--are diagnosed late, diagnosed terminal. So then a question hit me: this center will be for cancer, what if cancers cannot be cured, where will patients go? At that time I was finishing my Master’s degree in Nursing Education and Research, and I was working on my thesis on empathy, and I empathized really easily at that point. Next day I was talking to a friend of mine who has a Ph.D. in nursing, and we had the same questions. And then we started pulling interested people to ask this question--we just wanted an answer to this question. And we realized that we don’t see terminal patients at hospitals--where are they? They’re not in hospitals! So where are they?”

She began to understand that “in palliative care you do really care for a human being who is suffering. I don’t know why—maybe it’s the way the philosophy of palliative care makes it always easier to start at homes—it has started most of the places, the work, at homes, and it took a long time before it got integrated in hospitals.”

An important aspect of her work is to develop attentive communication and cultural sensitivity. With the support of two or three hospice workers from the US and UK to whom she feels very grateful, she was encouraged to develop a Jordanian model of palliative care that was culturally appropriate. As she says, “This is palliative care; it has spiritual and cultural issues.”

**Mazen Al Bashir—Medical Director: Al Malath Foundation for Humanistic Care, Amman: interviewed by Amanda Bingley, 12 May 2005 – duration of interview: 35 minutes.**

Mazen Al Bashir talks about his training as a general practitioner at the medical school in the University of Liverpool, UK and later his GP work in Liverpool. With Rana Hammad he discusses his dedication to providing holistic palliative care for the patients in the home hospice, describing how he often spends long hours with patients and their families. He talks of the importance of honoring

the dying process as a valid and vital part of medicine, as important as the birth process. As he says:

“You know, if one of my patients died without me attending, or he died unexpectedly, without really having family around, giving all the rituals...if it doesn’t happen that way, I don’t have that--if one of them died when I’m not there, it’s not exactly losing one of your young, new mothers in labor--if it happened to a gynecologist that he loses a young lady in labor, I mean, it’s the most humiliating experience--but it’s the same for me. But that’s exactly the spirit you need in any cancer hospital or in patient facility. It’s the most important job to make sure that those hours worked and this time--because it’s a crucial time--the finale--the grand finale, and without having the family there continuing to help, their reaction and their grief response won’t be the same.”

**Amal Bandak—Associate Director of Nursing & Patient Affairs at the King Hussein Cancer Center: interviewed by Amanda Bingley, 11 May 2005--duration of interview: 55 minutes.**

Amal Bandak is leading the first hospital-based hospice team in Jordan. She is Palestinian, and has lived and worked in Jordan since the late 1980s. With a background in pediatric oncology nursing and nursing education, her PhD was in maternal and child nursing. As she describes: “I used to teach at Jordan University until last year and then I decided to give up teaching, I want something new! Rena (the specialist nurse on the KHCC team) is one of my students; most of them are my students.” She talks about her experience nursing patients at the end of life and setting up volunteer groups supporting cancer patients in three hospitals in Amman. She is a psychotherapist, and is committed to use these skills to build a strong team. She notes that:

“In a short period of time we did a lot. And most important is that we are a group, a very committed group working together like one family. I’m very proud of them. We have a lot of problems but through this method [psychotherapy] we are able to solve many problems ... together we are able to build a very nice group.”

She is keen to promote training and has initiated positive links with palliative care courses with Frank Ferris at San Diego Hospice, US and in Canada.

**Ahmad Al Khateib—Director of Nursing Education: King Hussein Cancer Center, Amman: interviewed by Amanda Bingley, 11 May 2005--duration**

*of interview: 45 minutes.*

Ahmad Al Khateib talks about his work to promote education and training for the newly developing services in Jordan. He has a background in oncology nursing, with a Master's in Nursing Oncology from Georgetown, US, and hospital training in palliative care and patient education. He is currently doing a Ph.D. He became involved in KHCC when he was asked to coordinate a course in palliative care and liaison for the Ministry of Health, WHO and KHCC. He was nominated to coordinate the training programs and developing projects. As he says:

“I'm glad to do this... For me palliative care, I think it is part of symptom management, quality of life and not suffering. I think it is important from the belief that it is the patient's right to be cared ... I might not be able to cure, but that becomes a secondary objective or goal, but sometimes at least we could help alleviate suffering. The concept of palliative care... in Jordan and maybe all over the world, but in Jordan particularly, still it's a new concept. So it took us some time to help the physicians and nurses and health care providers to understand what you mean by palliative care and to emphasize that the patient it's part of their lives to die in peace and dignity. So even until the last minute you have to take care of the patients. We found some people who are really interested, and we work with these people who now attended the courses, and train them, because I think these people will be very helpful, to also convince other people. So now we have a program and training, so things become clear; before there was nothing.”

## ENDNOTES

1. 2002 population estimate Jordan Ministry of Health statistics – Al Kayed S and Al Hijawi B. Report of the National Cancer Registry, Incidence of Cancer in Jordan 2002, The Hashemite Kingdom of Jordan, Ministry of Health; 2005.
2. “Physicians' guide to hospice care” Al Maath Foundation information leaflet, 2005.
3. IOELC interview: Nisreen Al Alfı – 11 May 2005.
4. IOELC interview: Amal Bandak – 11 May 2005.
5. Clark JA (2004) Islamic associations and the middle class, ISIM newsletter 14, June 2004; 51 [www.isim.nl/files/news14/news14-51.pdf](http://www.isim.nl/files/news14/news14-51.pdf).
6. Center for Palliative Care Studies at San Diego Hospice, CA is supporting the Jordan Pain Relief and Palliative Care Initiative. <http://www.cpsonline.info/content/resources/jordan.html>.
7. 1,000 JD are equivalent to around \$1,411 (currency exchange 1 JD = \$ 1.41 – 11 July 2005).
8. Al Malath Operating Model - information on website [www.hospic.jubilee.edu.jo/operating\\_model.html](http://www.hospic.jubilee.edu.jo/operating_model.html).
9. IOELC interview: Ahmad Al Khateib – 11 May 2005.

10. IOELC interview: Bassam Hijawi – 11 May 2005 and IOELC interview: Rana Hammad – 12 May 2005.
11. International Narcotics Control Board. Narcotic Drugs: estimated world requirements for 2004. Statistics for 2002. New York: United Nations; 2004. International Narcotics Control Board. Report of the International Narcotics Control Board 2004, United Nations: New York; 2005. [www.incb.org/incb/en/annual\\_report\\_2004.html](http://www.incb.org/incb/en/annual_report_2004.html).
12. Selva C. International control of opioids for medical use European Journal of Palliative Care 1997;4:194-198.
13. “The term defined daily doses for statistical purposes (S-DDD) replaces the term defined daily doses previously used by the Board. The S-DDDs are technical units of measurement for the purposes of statistical analysis and are not recommended prescription doses. Certain narcotic drugs may be used in certain countries for different treatments or in accordance with different medical practices, and therefore a different daily dose could be more appropriate.” International Narcotics Control Board. Narcotic Drugs: estimated world requirements for 2004. Statistics for 2002.
14. International Narcotics Control Board. Narcotic Drugs: Estimated World Requirements for 2004. Statistics for 2002. New York: United Nations; 2004.
15. Stjernswärd J. Jordan: National Palliative Care Programme. Hospice Information Bulletin June 2004. Worldwide Hospice and Palliative Care Online (WHPCO) - a free, electronic newsletter published every two months for people involved or interested in international palliative care. For a sample copy, or to subscribe mail to: [anne@hospiceinformation.info](mailto:anne@hospiceinformation.info) or [avril@hospiceinformation.info](mailto:avril@hospiceinformation.info).
16. IOELC interview: Rana Hammad – 12 May 2005.
17. Ferris F and Stjernswärd J: presentation at the Open Society Institute (OSI) seminar, Budapest, Hungary, 5 –7 September 2005.
18. IOELC interview: Mazen Al Bashir – 12 May 2005.
19. ‘The concept of hospice care’ Al Malath Hospice information leaflet, 2005.
20. Al Malath Operating Model--information on website [www.hospic.jubilee.edu.jo/operating\\_model.html](http://www.hospic.jubilee.edu.jo/operating_model.html).
21. King Hussein Cancer Centre--information on website [www.khcc.jo/KHCCCenter.asp](http://www.khcc.jo/KHCCCenter.asp).
22. Stjernswärd J. Jordan: National Palliative Care Programme Hospice Information Bulletin June 2004.
23. Brown A and Kay J. The continuing care of the patient with advanced cancer, Unpublished manuscript; 1986.
24. Hammad R. The hospice experience in Jordan: Al Malath Foundation for humanistic care, In Saunders DC and Kastenbaum R. Hospice care on the international scene. New York: Springer Publishing; 1997, pp. 242-254.
25. Stjernswärd J. Jordan: National Palliative Care Programme Hospice Information Bulletin June 2004.

26. Ferris FD, Bower KA, Stjernswärd J. Integrating palliative care into an existing healthcare system: an international perspective. Paper presented at the AAHPM, New Orleans, LA, January 23 2005.
27. King Hussein Cancer Center training manual and guide--draft--compiled by Amal Bandak and members of the KHCC hospice team, May 2005.
28. IOELC interview: Carol El Jabari – 10 March 2005.
29. IOELC questionnaire: Suha Omran – 8 August 2005.



# Chapter 8

## Palliative Care in the Palestinian Authority

The Palestinian Authority refers to two separate land areas in the Middle East. The Gaza Strip (population 1,324,991) covers an area of 360 square kilometers bordering the Mediterranean Sea between Egypt and Israel. Its land boundaries border Egypt and Israel. The West Bank (population 2,311,204) covers an area of 5,860 square kilometers bordering the Dead Sea. Its land boundaries border Jordan and Israel.

### PALLIATIVE CARE SERVICE PROVISION

#### Current services

There are no specific palliative care services in the Palestinian Authority. The charitable non-governmental organization (NGO), the Patient's Friends Society-Jerusalem (PFS) located inside the Augusta Victoria Hospital in East Jerusalem, offers psychosocial support, advice and education.

There are six oncology units in general hospitals around the West Bank and the Gaza Strip, which provide pain and symptom relief for adults at the end of life. Two of

the units in the Gaza Strip also care for children (Table 8.1).

Hospital oncology units: There are six oncology units which offer pain and symptom control at the end of life. The Augusta Victoria Hospital in East Jerusalem, which has a government-funded oncology unit, treats around 100 cancer patients per year.

There are two government-funded units in the Palestinian Authority West Bank, Beit Jala Hospital and Nablus Hospital (no patient numbers available). There are three government-funded units in the Gaza Strip, which between them treat an estimated 700 patients per year; around 55% of patients in the north of Gaza access services at





**Illustration 8.1: Augusta Victoria Hospital, East Jerusalem**  
[photograph: Amanda Bingley, May 2005].

the Shifa Hospital and a pediatric oncology unit at the Nasser Hospital, and around 45% of patients in the south of Gaza access services at the European Gaza Hospital, which also treats children.

Palestinians may also access palliation via Israeli services if they live in East Jerusalem and have an Israeli identity card and health insurance. If patients have the means to pay, there are oncologists who run small private oncology clinics in the West Bank or patients are given referrals to services in Jordan, Egypt and other countries overseas.

The Patient's Friends Society, Jerusalem (PFS), focuses on women's health and public health through health education and psychosocial support. Services include breast cancer and osteoporosis screening, lectures, advice about cancer via health education literature and a Helpline service, self-help groups for women with breast cancer in the West Bank, newsletters and seminars for physicians and other health professionals working in, for example, small clinics around the West Bank, some of which may be supported by other NGOs and UN organizations. Where possible, PFS offers psychosocial support to women with cancer at the end of life.

There is no reported palliation or support for patients with other illnesses including heart disease and stroke. At the time of writing, the incidence of HIV/AIDS is reportedly still very low but supportive care is provided if needed. (2)

### Reimbursement and funding for services

Augusta Victoria Hospital is part funded by government and part funded by charitable donations. The Oncology Department is government-funded. The hospital is resource poor and relies heavily on donations for equipment and development of existing services.

The Patient's Friends Society is a registered charity non-profit NGO. The PFS charges a nominal fee for breast

**Table 8.1 Palliation and palliative support available to Palestinians 2005**

Adult and Pediatric* Services							
	Freestanding unit	Hospital unit	Hospital support team	Home care	Day care	Drop-in / Advice Center	Grand Total
<b>Palestinian Authority-funded oncology units:</b>							
<b>West Bank</b>		1					1
~ Beit-Jala Hospital		1					1
~ Nablus Hospital							
<b>Gaza Strip</b>							
~ European Gaza Hospital*		1					1
~ Shifa Hospital		1					1
~ Nasser Hospital*		1					1
<b>Charitable funded provision:</b>							
~ Augusta Victoria Hospital oncology unit		1					1
<b>NGO</b>							1
~ Patient's Friends Society						1	1
		6				1	7

and bone density screening services. All other services are provided free.

The Palestinian Authority funds hospital services in government hospitals in the West Bank and Gaza Strip. Oncology patients are eligible for free treatment via their government health insurance. There is a small charge for some medications during cancer treatment.

### Opioid availability and consumption

The Palestinian Authority is not an independent sovereign state and thus not an acceded party to the conventions of the International Narcotics Control Board which therefore has no published figures for the consumption of narcotic drugs in the Palestinian Authority. The proportion of consumption via Israeli license--and thus accounted for in Israeli returns--is not defined.

Oncologists report that the available range of drugs in 2005 for pain at any stage of disease can include:

morphine hydrochloride by injection 10 mg and 20 mg; MCR oral tablets--more commonly used than injectable morphine--(morphine sulphate as a controlled release system 10 mg and 30 mg)

Dolestine (pethidine hydrochloride) by injection 50 mg and 100 mg

Percodan oral tablets (a combination drug containing oxycodone and aspirin); these are widely used throughout Gaza and the West Bank.

Opioids of choice when available at the end of life include injectable fentanyl 2 mg, 10 mg (ampoules), and pethidine 50 mg (ampoules). The opioid antagonist naloxone is used if needed (2).

Opioids are available to patients at the Augusta Victoria Hospital, East Jerusalem. However, availability for outpatients is dependent on the authority of an Israeli license holder and is also compromised by the ability of the patient to pay, as one of the oncologists explains:

“The main problem that we have is the availability of pain medications, especially morphine. We are in a difficult situation, because here it’s a Palestinian hospital but it’s in Israeli territory, so we cannot get morphine, so I don’t have, let’s say, the authority to prescribe morphine. I can do it here inside the hospital, but if I want a patient to take morphine when he goes home, then officially I can’t do that, I have to wait for somebody with an Israeli license to come do a prescription. We do have somebody on the

staff here who has an Israeli license, but he’s not available all the time. That’s not the only problem: another aspect is really most of our patients don’t have permits to go to West Jerusalem, and that’s where the pharmacy is. So even when we do get a prescription written, there are problems how to go and get it, and it’s kind of expensive because the average morphine prescription will cost a patient around probably 50 euros. Maybe that’s not expensive by your standards, but for our people here it’s really expensive. And of course there are restrictions, so sometimes people at the pharmacy will not give more than two weeks’ supplies, so the patient has to keep on going back and forth to the pharmacy. So that’s a big problem for us.” (1)

### Palliative care coverage

Currently there are no dedicated palliative care services in any area of the Palestinian Authority. Palliation is supported in six oncology units. As one oncologist stated, there is acute need as “the majority of cases are at an advanced stage, requiring palliative care--but we have no palliative care services, or trained people.”

### Palliative care workforce capacity

There are no available figures for workforce capacity.

## NATIONAL AND PROFESSIONAL ORGANIZATIONS

The Patient’s Friends Society, Jerusalem (PFS), is a Palestinian non-profit non-governmental organization (NGO) established in 1980 by Palestinian academics and health professionals to promote health care services. The PFS is the only health-related NGO that offers, among its other public health education and cancer support work, psychosocial support for women with cancer at the end of life. Since the early 1990s the focus of PFS-Jerusalem has been on women’s health and in particular supporting women with breast cancer in the West Bank and Gaza. (6)

Located in East Jerusalem at the Augusta Victoria Hospital, PFS offers a range of health education outreach services and literature to promote cancer prevention; a mammography screening service for early detection of breast cancer and bone density screening for osteoporosis. An important development since 2000 is the setting up of the “Sunrise” (*Shuruq*) breast cancer survivors’ support group for Palestinian women. In 2002, women in the Sunrise group set up a Helpline for information and advice, which by 2005 had been shown to be very successful. They have a current membership of 50 can-

cer patients including survivors. There is a “Reach for Recovery” program, where trained volunteer survivors offer support to breast cancer patients. PFS also offers low cost wigs and prostheses to breast cancer patients. (13) Director Carol El Jabari explains that PFS can only offer limited support at the end of life; in this situation PFS volunteers will offer psychosocial support and sometimes may be able to help access oncologists to prescribe pain relief. (15)

PFS is committed to training and professional development and research around cancer and women’s health, organizing occasional short seminars for health care professionals; and self-help workshops teaching first aid, Reiki healing and self care. Since 2002, representatives from PFS have regularly attended the conferences of the International Union against Cancer (UICC). For example in 2002, PFS participated in a presentation of findings of the “Project COPE” Israeli/Palestinian study, funded by MECC, “Coping with breast cancer among Palestinian and Israeli women” at the 18th conference of the UICC held in Oslo. In 2004, Carol El Jabari, the Director of the Society, presented at the UICC World Conference for Cancer Organizations in Dublin, Ireland with a workshop entitled “Cancer Patient Support Groups in Palestine and Jordan.” In 2005, PFS Director Carol El Jabari and Amy Avgar of the Israel Association for the Advancement of Women’s Health, sponsored by MECC, published an evaluation of the Project COPE study. PFS also distributes a twice yearly newsletter to members, volunteers, and health care professionals.

Augusta Victoria Hospital, located in East Jerusalem, is a charitable hospital managed since 1950 by the Lutheran World Federation. Its history and development is described as:

“Built in 1907 as a pilgrims’ hospice by Kaiser Wilhelm II in honor of his wife the Empress Augusta Victoria, it was converted into a hospital for the British Army during WW2. In 1948, the International Committee of the Red Cross established it as a hospital for displaced Palestinian refugees. In 1950, the United Nations Relief and Works Administration (UNRWA) took over responsibility for Palestinian refugees. Today, 75% of the hospital’s referrals are made by UNRWA. Since 1993, Augusta Victoria has been providing services to the local and greater Palestinian community... In cooperation with UNRWA, and through an assessment of the needs of West Bank communities, Augusta Victoria Hospital is developing the first radiation oncology center available in all of the Palestinian territories, as part of the expansion of the hospital’s Oncology Department.” (18)

The Augusta Victoria is a general (medical and surgical) hospital with 100 beds. Facilities include a renal dialysis unit for children and an oncology department run by Medical Oncologist Dr. Fouad Sabatin, who treats around 100 cancer patients every year. He describes the current situation:

“This number [of cancer patients] is supposed to double or treble very soon because we are going to be the only radiation oncology department in the West Bank, so we are expecting that most, if not all the patients will be referred to us. They will still go to [oncology units in the West Bank] for chemotherapy, it’s just these places don’t have radiation therapy; they have to come to us for that. We have a medical department; we admit patients with medical conditions and oncology conditions to that department, and it’s really variable, so sometimes these beds are 100 percent occupied by oncology patients and other times 20 percent, so it’s variable. In the next one or two months [from May 2005], we [will] make a specific requirement for oncology patients.”

Dr. Sabatin will provide palliation at the end of life in the hospital. He explains the difficulties of providing palliative support:

“If they have severe pain we keep them and get their pain under control, but eventually they will be discharged. But one of the problems here that is we don’t have hospice care, so there are a lot of patients who are candidates for that kind of care, but it’s not available. So I would say that towards the end of life, what happens is that these people, they tend to come frequently to the hospital because when they go home their pain’s no longer under control and because it’s unfortunate we cannot, 99 percent of our patients cannot afford to pay for the Fentanyl patches, for example. Sometimes they have side effects from the morphine and in that situation we are stuck. So these people come back into hospital because they don’t have a lot of choices. So that’s the main point--these people, instead of being in a good hospice program, they end up visiting the emergency room frequently.

“I’m the only medical oncologist here at the Augusta Victoria Hospital, so it’s natural that I have to take care of, to palliate patients, not only give them chemotherapy but even after that, like during therapy if they have a pain, and after they’ve done the therapy, they can also have pain. Or even if they are not candidates for chemotherapy or aggressive therapies they still need to [have] palliative care. So it’s like [an] important part of my job here to do the palliative care for patients.” (1)

There are considerable difficulties of access for staff to get to work at the hospital and for patients to get to services at the hospital if the checkpoints into East Jerusalem are closed. This is particularly serious if they are dialysis patients, as the hospital has the only dialysis center for children in the West Bank. But access poses a tremendous problem for cancer patients, especially those at the end of life who are not living near an oncology unit:

“People living in Ramallah are unlucky when it comes to having a diagnosis of cancer because there is no center in Ramallah with the facility to treat these patients, and typically, these patients need to be referred to Beit Jala hospital or to Nablus, and all of them are far away, and there are several checkpoints in between. So getting to the hospital is really difficult, and usually it takes several days for these patients to be sent in the right direction. Now, these patients have a choice to come to Augusta Victoria Hospital, but obviously not all of them will be sent to us because we’re not a government hospital. So most of the patients, I would say, will be sent to Beit Jala or to Nablus Hospital. And if you’re asking about how these patients will do and their management, if they have a pain crisis or something like that, it’s really very tough because, as I said, there is no place in Ramallah that’s really able to treat these patients. They end up being treated by general practitioners at government hospitals until they can be referred to another place. It’s a sad situation.” (1)

The Middle East Cancer Consortium (MECC), of which the Palestinian Authority has been a member since 1996, provides support in several different areas: establishing standardized cancer registries in member countries, as well as sponsoring and supporting training and development in cancer registry and cancer services. In February 2004, MECC convened a two-day conference in Larnaca, Cyprus, specifically to discuss the concept of palliative care and to initiate assessment of palliative care services and needs in the member countries.

## EDUCATION AND TRAINING

There is no formal program of palliative care training. The PFS has run occasional day seminars for doctors and nurses, a component of which includes psychosocial support for breast cancer patients. Oncologists travel to international conferences and seminars for training. The Middle East Cancer Consortium convenes conferences and seminars for training in cancer registry and other aspects of cancer diagnosis and treatment, including the conferences on palliative care in February 2004 and November 2005, at Larnaca, Cyprus.

## ETHICAL ISSUES

There are two major ethical issues described by health care professionals providing end-of-life support in the Palestinian Authority. The first is the problem of health service provision when working in an area riven by conflict, and with no home care support. The second is the problem of disclosure of the diagnosis and prognosis to cancer patients. Dr. Fouad Sabatin discusses these two ethical problems:

“Sometimes the families also can ask us not to tell the patient he or she has cancer and we end up having to deal with the situation because the patient doesn’t know if he has a tumor. Eventually they will know they have a terminal illness, but for the families the pressure is so hard not to tell the patient. So the families they take that role, they try to take decisions for the patient. I try my best to avoid that. I love it when I get to the patient first before a family member comes to me and says, ‘Oh please, don’t tell him that he has so-and-so.’ And in certain situations that has happened, so that’s number one. Number two, these families, most families they don’t have support; for example, although we have a social worker on the staff, but we don’t have enough support and resources for these people and because the insurance system is not great, once these patients go home they don’t have the luxury of having like a visiting nurse or sometimes having physiotherapy at home or home care or for example home equipment and so on. So sometimes the families get overwhelmed. But this is probably different from the Western countries, most of the families here are committed, so they really take care of the patients very well, but it’s a hard job.” (1)

Carol El Jabari suggests that much of the problem relating to disclosure is due to lack of training for doctors. She also feels that the lack of access to care is a major issue:

“A major ethical issue is that the doctors are not frank with the patient; they don’t tell them they have cancer. It is a major obstacle we as caregivers have to try and overcome when trying to give palliative care or any kind of care. Usually the family will know, and the family tells the doctor, ‘Please don’t tell them.’ Most of the patients know--won’t they figure out when they go for chemotherapy or radiotherapy? While most people don’t want to say or hear the word ‘cancer’ we have found in our experience it is best to tell the patients, so they can get on with the rest of their lives. Most of the doctors have never been trained to discuss such a major health issue so they need skills and sensitivity training to better deal with patients and families. We’ve had some workshops with nurses. The nurses we’ve been teaching are great,

but they're all very frustrated because they're dealing with patients the doctors haven't told.

“Another ethical problem is that the access to care, whether it be for diagnosis, chemotherapy, radiotherapy or psychosocial support, depends on the individual being well enough to go obtain a permit, have it accepted at the barriers and eventually get to their treatment. This is all very traumatic, disheartening and exhausting.” (6)

## HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

### Narrative history of palliative care

Palliative care remains an undeveloped and under-resourced area of health care in the Palestinian Authority. There are, however, several dedicated oncologists and also PFS volunteers who strive wherever possible, often against the odds, to provide some palliative and psychosocial support for cancer patients at the end of life.

There are concerns at the lack of palliative care training and the subsequent lack of awareness of needs. Senior Oncologist Dr. Abdel Rassaq Salhab has explained that he had to develop his palliation skills, in the form of pain relief and symptom control, by attending international seminars and short training courses abroad. As he noted there is a need for “a national program of palliative care and to have a dedicated society for hospice care.”

Efforts by MECC and PFS since the early 2000s offer some opportunities for greater awareness of the need for specialist care and training at undergraduate and professional level.

Dr. Fouad Sabatin describes his hopes for the future:

“What I would really want to see change is to have a team approach for cancer care, to have more resources. We have a lot of trouble giving chemotherapy so I hope that in the future we can give chemotherapy easier, and hope that the radiation and oncology unit starts running very soon. And when it comes to palliative care medicine, I really hope that we can come to an agreement with the Israeli people who can give me some authority to write prescriptions and I hope that somehow the price for morphine is not as high as it is now because I think it is one of the basic medicines and should not be expensive. And also I'd love for my patients to have all the options available for patients who are intolerant of morphine, to have the opportunity to resort to fentanyl patches, to oxycodone and sometimes methadone. Also I'd really

love to witness the day when we would have a hospice program here. So as you see, we have a lot of things to look forward to.” (1)

## LIFE/ORAL HISTORIES

### Patient's Friends Society

*Carol El Jabari, Director, Patient's Friends Society (PFS), Jerusalem: interviewed by Amanda Bingley--10/03/05--duration of interview: 25 minutes*

Carol El Jabari talks about her work with the PFS and how she became interested in psychosocial care. She explains:

“I'd started working with the Patient's Friends Society in the late '80s, and in 1990 we started the first mammography center in Palestine. I identified women coming through being diagnosed with cancer and knew they had no psychosocial support, amongst other things, so it was a service I was really very keen to develop. It wasn't until 2000 that it became a reality because it was important to identify women that were as keen, or committed as me to make it happen. My educational background is nursing and psychology and public health, so it all came together.”

She describes the very successful model for support groups for women with breast cancer that she and other volunteers have developed based on the Reach to Recovery model and introduced by the Israel Cancer Association, noting what a tremendous difference the service has made for the Palestinian women involved: Importantly the program has been adapted to meet Palestinian needs and culture.

“The women who are part of the group are so happy. If I told them to come three times a week, they'd be here in a shot, because it's made such a difference to their lives, you know, because it's empowering. They participate in activities they never had the chance to do before such as fund-raising events, attending conferences, and workshops. For many of the women the diagnosis of cancer meant death. Now they are living productive, happy lives.”

Carol explains that she is now also able to teach this model of self-help at the King Hussein Cancer Center (KHCC) in Jordan. She has taught 11 women to be Reach to Recovery volunteers in addition to attracting over 30 women to the SANAD support group.

## REFERENCES

- Avgar A & El Jabari C. The impact of an Empowerment Model on Palestinian and Israeli women coping with breast cancer: survey results and evaluation, MECC-sponsored study for Project COPE, 2005.
- Rockoff Y, El Jabari C, Avgar A, Ziv M, Barnea T. Coping with breast cancer among Palestinian women and Israeli women: Project COPE, Final Report, Phase A, 2000-2003, 2004.
- Stjernswärd J & Clark D. Palliative medicine – a global perspective. In: Doyle D, Hanks G, Cherny N, Calman K (eds.) Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press, 2003.
- [www.who.int/cancer/palliative/en/](http://www.who.int/cancer/palliative/en/)

## ENDNOTES

1. IOELC interview: Dr. Fouad Sabatin – 2 May 2005
2. Email communication: Dr. Khamis Najjar, European Gaza Hospital – 17 October 2005
3. Email communication Dr. Al Zakzuz – 21 July 2005
4. Bendel, M. The disengagement plan and its repercussions on the right to health in the Gaza Strip. 2005.  
[www.phr.org.il/phr/files/articlefile\\_1123056289960.pdf](http://www.phr.org.il/phr/files/articlefile_1123056289960.pdf)
5. Information leaflet “Patient’s Friends Society Jerusalem” PFS.
6. IOELC interview: Carol El Jabari, Director PFS--10 March 2005
7. United Nations. Report of the International Narcotics Control Board 2004, New York: United Nations, 2005.  
[www.incb.org/incb/en/annual\\_report\\_2004.html](http://www.incb.org/incb/en/annual_report_2004.html)
8. International Narcotics Control Board. Narcotic Drugs: estimated world requirements for 2004. Statistics for 2002. New York: United Nations, 2004.
9. Selva C. International control of opioids for medical use European Journal of Palliative Care 1997;4(6),194-198.
10. Email communication Dr. Al-Zakzuz--21 July 2005--for details on the drug combinations referenced also see  
[www.rxlist.com/cgi/generic/oxyasa.htm](http://www.rxlist.com/cgi/generic/oxyasa.htm)
11. For details on the list of accessible opioids see  
[www.moh.gov.ps/index.asp](http://www.moh.gov.ps/index.asp)
12. Dr. Al-Zakzuz in discussion MECC conference, Larnaca, Cyprus (February 2004)
13. Patient’s Friends Society website 8 February 2005  
[www.pfsjer.org/home.htm](http://www.pfsjer.org/home.htm)
14. Patient’s Friends Society health education publications – all listed below are available on request from PFS  
[www.pfsjer.org/publications.htm](http://www.pfsjer.org/publications.htm)  
*Reports on studies conducted by PFS:*  
PFS Prevalence of breast disease among Palestinian women, 1994-1996; 1999.  
PFS The demographic characteristics and self reported symptoms and behaviors of mid life Palestinian women. 2000. (financed by the South African Representative Office, Ramallah).  
*Publications for healthcare professionals:*

- PFS National Guidelines for breast cancer screening, 1999.
- PFS Breast cancer screening – a practical guide for primary health care physicians. 1999.
- PFS Mammography techniques for X-ray technologists. 1999.
- Public health leaflets (in Arabic) (cancer-related information leaflets are sponsored by the National Cancer Institute, Bethesda): Exercises after breast surgery; Iron Deficiency anemia; Breast self-examination; Look after yourself; Food safety; Pain and breast lumps--more information; Adolescence; Midlife women; Osteoporosis; HIV/AIDS; You and your child; Your life after breast cancer; Me and my family--living with cancer
15. IOELC field visit with Carol El Jabari, Director PFS – 2 May 2005
  16. El Jabari, C. (2005) Patient’s Friends Society Sunrise Group – Breaking the Silence, Bridges: Israeli-Palestinian Public Health Magazine 1(2), 26, February-March  
[www.healthinform.net/files/Bridges/bridges02.pdf](http://www.healthinform.net/files/Bridges/bridges02.pdf)
  17. Project COPE is a joint Israeli-Palestinian initiative concern with the needs of breast cancer survivors and the professionals who care for them. “The project is supported by the JDC-International Development Programme (IDP), the Andrea and Charles Bronfman Philanthropies, Edythe Grodnick, Dr. Alfred and Isabel Bader and the British Consulate in Jerusalem and others.” See Rockoff et al., 2004; Rockoff Y, Project COPE: Coping with breast cancer among Palestinian and Israeli women, Bridges: Israeli-Palestinian Public Health Magazine 2005;1:26. [www.healthinform.net/files/Bridges/bridges02.pdf](http://www.healthinform.net/files/Bridges/bridges02.pdf)
  18. Rockoff Y, El Jabari C, Avgar A, Ziv M, Barnea T. (2004) Coping with breast cancer among Palestinian women and Israeli women: Project COPE, Final Report, Phase A, 2000-2003
  19. [www.pfsjer.org/conferences.htm](http://www.pfsjer.org/conferences.htm)
  20. Avgar A and El Jabari C. The impact of an Empowerment Model on Palestinian and Israeli women coping with breast cancer: survey results and evaluation. MECC-sponsored study for Project COPE; 2005.
  21. Patient’s Friends Society (PFS) Jerusalem Newsletter January–June 2005. [www.pfsjer.org/news/pfs\\_2005\\_june.doc](http://www.pfsjer.org/news/pfs_2005_june.doc)
  22. The Lutheran World Federation (LWF) has been running the AVH since 1950. The health institution is one of the projects of the LWF Department for World Service (DWS) program in Jerusalem. Around 75% of the Augusta Victoria Hospital patients come from the West Bank.  
[www.lutheranworld.org/news/lwi/en/1589.en.html](http://www.lutheranworld.org/news/lwi/en/1589.en.html)
  23. IOELC Questionnaire, February 2004 – MECC conference, Larnaca, Cyprus.



# Chapter 9

## Palliative Care in Turkey

Turkey (population 68,893,918) is located largely in south-western Asia, and also in southeastern Europe from west of the Bosphorus. Turkey covers an area of 780,580 square kilometers bordering the Black Sea between Bulgaria and Georgia, and bordering the Aegean and Mediterranean Seas between Greece and Syria. Land boundaries border Bulgaria and Greece to the west; Georgia, Armenia and Iran to the north and west, and Iraq and Syria to the south.

### PALLIATIVE CARE SERVICE PROVISION

#### Current services

There are no specialist palliative care services in Turkey. Medical oncology units and departments of algology (pain) in major hospitals in the country provide pain control and symptom relief. Oncologists and pain specialists in seven

hospitals report active working to establish the concepts of palliative care (Table 9.1).

Development of palliative care tends to be focused around cancer patients in oncology units and algology (pain) departments and centers. The majority of cancer patients are treated in university hospitals that support units with pain specialists and medical oncologists. Pain centers and departments also offer palliation for patients at the end of life with other illnesses. Some specialist cancer state hospitals such as the Dr. Ahmet Andicen Oncology Hospital and Demetevler Oncology Hospital will provide pain relief and symptom management. No information, however, is currently available about the development of palliative care services in the state hospital system or the development of training in the 57 medical schools around the country (11). There are around 30 specialist “pain centers” and 20 medical faculties with departments



Table 9.1 Palliation in Turkey 2005 (hospitals with some active development of palliative care concepts)

Adult Services							
	Freestanding unit	Hospital unit	Hospital support team	Home care	Day care	Clinic/ Drop-in center	Grand Total
Başkent University Hospital, Ankara		1					1
Gazi University Hospital, Ankara		1					1
Gulhane Military Academy, Ankara		1					1
Hacettepe University Hospital, Ankara		1					1
Istanbul University Medical Faculty		1					1
Marmara University Medical Faculty , Istanbul		1					1
Pamukkale University Medical Faculty, Denizli		1					1
<b>Total</b>		<b>7</b>					<b>7</b>

of algology in Turkey. There are no reported activities for pediatric palliative care.

Individual physicians and their colleagues are actively involved in developing the concepts of palliative care within departments and units in three main areas of the country; in Ankara, a pain specialist at Hacettepe University Hospital, three oncologists, one at Başkent University Hospital, one at the Gulhane Military Academy (GATA), and one at Gazi University Hospital; in Istanbul, a pain specialist at the Istanbul University Medical Faculty and two oncologists at the Marmara University Medical Faculty; there is one pulmonary specialist developing concepts of palliative care at the Pamukkale University Medical School, Denizli. Medical and nursing professionals have also expressed interest in palliative care at Ankara University Faculty of Medicine.

### Başkent University Hospital Faculty of Medicine, Ankara

Başkent University, founded in 1993 through the cooperation of the Turkish Organ Transplant and Burns Treatment Foundation (established in 1980) and the Hasberal Education Foundation, runs a large university hospital in Ankara with several other sites around the country. A broad spectrum of up-to-date diagnosis and treatment in all fields of medicine is provided including oncology and algology. Medical oncologist Professor Özgür Özyilkan, chair of the Medical Oncology Department, is encouraging palliative care approaches in his unit. Professor Özyilkan is also a founding member of the Turkish Oncology Group.

### Gulhane Military Academy (GATA), Ankara

Medical oncologist Dr. Seref Komurçu is providing palliation in the 33-bed oncology unit at GATA, a large (1500 bed) military hospital in Ankara. The oncology unit has a staff of seven physicians and 18 nurses. They treat around 1200 patients annually with around 100 inpatients every year requiring palliation at the end of life. Dr. Komurçu explains that at GATA:

“We don’t have a separate unit for palliative care, but we need it. I’m mostly involved in palliative care, and I’m preparing a project to set up a separate unit, but it’s not easy. We need a separate floor and some other personnel, so I think it will take some time, a couple of years maybe. I do palliative care in that department and we follow the terminal patient also in the department. End-of-life care is done in the inpatient situation and most of the patients stay at home at their end-of-life period, and some patients prefer to stay at hospital in their terminal phase, and we apply terminal sedation sometimes. We don’t have a home care program; our insurance on each level doesn’t cover the home care program. But some new regulations are being [developed] and maybe after this year the general insurances will cover home care treatment.”

### Hacettepe University School of Medicine, Ankara

Pain specialist and surgeon Dr. Osman Abbasoglu is involved in encouraging a palliative care approach in the

Department of Anesthesiology. The department offers a “pain relief service with one assistant professor in charge.” Dr. Abbasoglu explains that he works with adults, seeing around 400 patients each year, “about 80 percent are inpatients, 15 percent day care, and 5 to 10 percent home-based.” Patients are referred to the department for palliative pain relief by other physicians, “more than half have cancer, about 25 percent chronic diseases like COPD.” The physicians can call on a social worker to support a patient if they perceive a need. There are plans to build an inpatient hospice unit at the Hacettepe.

### **Gazi University Hospital, Ankara**

Medical Oncologist Dr. Deniz Yamaç, based at the 20-bed oncology unit, specializes in head, neck, and breast cancer. While she offers pain relief and symptom control, she is also actively developing palliative care training for doctors, nurses and students. Dr. Yamaç reports that at this time there are no funds to develop the service in the way she hopes; for example, by employing a psychologist or setting up home care support. Working as part of a six-doctor team, Dr. Yamaç sees up to 100 patients a week, around 10 of whom need end-of-life palliative care.

### **Marmara University Medical School Hospital, Istanbul**

With 350 beds, Marmara Hospital’s services include a 14-bed oncology outpatient unit, where medical oncologists Dr. Perran Fulden Yumuk and Dr. Nazim Turdal are actively developing the principles of palliative care. They are part of a team which includes three medical oncologists, two medical fellows, seven nurses, a psychologist, a pharmacist, a data manager and two secretaries. They see around 1000 new cancer patients a year and they write, “We are also following our patients who need palliative care and try to give them support for their pain management, nutritional status, etc. We try to be with our patients and relatives from the beginning of their disease till the end with all our team.”

### **Istanbul University Faculty of Medicine, Istanbul**

Pain specialist and Chairman of the Department of Algology Professor Serdar Erdine has developed pain relief, known in Turkey as algology, as a specialty. In his 14-bed unit they see around 3000 patients each year referred from other departments for pain relief. Around 1000 are cancer patients, most of whom are at the end of life. The remainder are patients with chronic pain from other illnesses. He follows the WHO “analgesic ladder” when prescribing. His aim is to support patients to have

sufficient pain relief at the end of life so they can be cared for at home (3).

### **Pamukkale University Hospital Medical School, Denizli**

Pulmonary specialist Dr. Sevin Baser is keen to develop training for department staff, medical and nursing students in the concepts of palliative care. His enthusiasm follows his own specialist palliative care training in the US. The hospital sees a high number of patients with late stage lung cancer who need palliation. There is no medical oncologist and, as yet, no dedicated palliative care (2).

## **REIMBURSEMENT AND FUNDING FOR SERVICES**

Services currently providing palliation are largely based in university hospitals, which are government funded. Patients in university hospitals either have to pay for treatment and medication themselves privately or their costs may be partially (or completely) covered through one of three government health insurance schemes, by the Green Card scheme, or by private insurance.

Free inpatient treatment and medication in university hospitals is available for people on low incomes if they have been issued a government Green Card. Outpatient-prescribed medication has to be paid for by the patient, who may be covered by their health insurance. End-of-life medical support accessible in Ministry of Health hospitals is free for inpatients, if they are insured or have a Green Card. There are a few home care services run by private health companies who also offer palliative care, but these are not reimbursable by government insurance plans.

The health system is highly complex in Turkey, with access to government health insurance schemes dependent on location and also on whether the patient is, or has been, a government employee. More government-funded services are found in the three largest cities. Where government-funded provision exists, there are more likely to be free or subsidized primary care and inpatient services. There are no reports of charitable palliative care non-government organizations (NGOs). In 2003, one cancer NGO, the Association of Patients with Cancer, was reportedly able to offer some financial help for cancer patients in need.

## OPIOID AVAILABILITY AND CONSUMPTION

Opioid preparations are available for patients at the end of life. Turkey has a color-coded prescription system: red prescription sheets for opioids, green for sedatives and opioid derivatives like tramadol. White prescription sheets are used for all other drugs. There is a dosage limit of no higher than 400 mg morphine in any one dose. Supply is limited to no more than 10 ampoules of morphine per prescription, no more than 24 tablets of codeine 40 mg, and no more than three packs of drugs over 7–10 days (3).

Deniz Yamaç, medical oncologist at Gazi Hospital explains that they use a full range of medications including MST, morphine, and oral, injectable, and pumps as IV infusion, fentanyl (transdermal patches), sevredol, and oxycodone. The Department of Algology at Gazi uses intrathecal injections but the unit does not use subcutaneous infusions.

Dr. Seref Komurçu, medical oncologist at Gulhane Military Academy, reports that in addition to oral opioids, they use epidural catheter in some patients. Professor Serdar Erdine explains that although they can prescribe fentanyl patches, slow release oral morphine and tramadol: “short-acting opioids are not available, like methadone.” In his Algology Department in the Medical Faculty of Istanbul, he reports:

“We implant [morphine] pumps (intrathecal, epidural) for cancer. In our center [since the mid-1990s] we have performed more than 1000 [insertions of pumps] for cancer. Plus, we do all types of nerve blocks. In a year we see 1000 patients with cancer, but we do only 100 [nerve blocks] for cancer. We obey the rules of the WHO step system. Not much use of the subcutaneous infusion because we see patients before the end of life, [although] the Oncology Departments are aware of our Pain Department and refer patients, and usually they are at a very late stage when diagnosed.” (3)

Professor Erdine has seen a change since the transdermal patches became available in Turkey. Before patches were available, he saw more patients for pain relief at an earlier stage in their treatment, but now the Oncology Department only refers to the Pain Department patients who, for example, are no longer having their pain relieved by the patches.

## PALLIATIVE CARE COVERAGE

Supportive care with pain relief is being developed mainly in university hospitals in Ankara and Istanbul—the two largest cities in the more populated western area of Turkey.

## PALLIATIVE CARE WORKFORCE CAPACITY

As of 2005, there are no specialist palliative care physicians, nurses, or related professionals in Turkey. Some individual medical oncologists and pain specialists are active in promoting the training of colleagues (doctors, nurses, psychologists, medical and nursing students) in the concepts of palliative care in their departments.

## NATIONAL AND PROFESSIONAL ORGANIZATIONS

The Turkish Oncology Group (TOG) was established in 1989. The Group works to encourage education about cancer and has several different sections which focus on different cancers. In the late 1990s the Group initiated a section on palliative care training and development. In October 2004 the Group dedicated a conference to the continuing development of palliative care in Turkey. The conference was co-sponsored and supported by the Multinational Association of Supportive Care in Cancer (MASCC) and co-chaired by Dr. Eoin Tiernan with Dr. Declan Welsh and TOG president Dr. Dincer Firat. As representative of MASCC, Dr. Eoin Tiernan explains:

“This key conference coincided with the unveiling of architectural plans for Turkey’s first hospice unit, to be opened in Ankara. Though home care, hospice and palliative care are not yet well-developed in Turkey, the high attendance and obvious support from prominent members of the oncology community in Turkey for the meeting gave ample evidence of the clear determination of TOG to advance both palliative and supportive care issues. The very well-organized program covered a wide range of topics in supportive care, including both physical and psychological symptom management, with a distinguished faculty of speakers. Dr. Matti Aapro, President of MASCC, also contributed to the program presenting updates on current approaches to anemia and emesis. One of the main purposes of the meeting was to explore the challenges in organizing and developing home care and hospice programs in Turkey. In keeping with this, international perspectives on home care and hospice development were presented by Dr. Declan Walsh (US),

Dr. Eoin Tiernan (Ireland), and Julia Anne Walsh (US). Perspectives on organization of home care and hospice in Turkey were presented by a number of professionals working in innovative programs in Turkey, and the sessions were followed by lively debate and discussion, with a representative from the Ministry of Health contributing. The meeting was also supported by Ms. Guldal Aksit, a Turkish government minister, who made a formal address pledging government support for this very important initiative.”

## EDUCATION AND TRAINING

There are a number of medical oncologists and pain specialists involved in developing palliative care education and training within existing hospital oncology and pain units.

### Gazi University Hospital, Ankara

Dr. Deniz Yamaç, who was introduced to the concepts of palliative care while completing training in oncology at the Arkansas Cancer Institute (Arkansas, US), has been running short sessions and day workshops from her oncology unit since 2000. These are designed for other medical faculty members and resident physicians. There is a separate program for medical students. In 2005, Dr. Yamaç began workshops for nurses in the oncology unit. She is also involved in a project—starting in 2005, funded by private health insurance—to train nurses in home care for cancer patients.

### Istanbul University Faculty of Medicine, Istanbul

Professor Serdar Erdine is actively involved in public and professional education, promoting the principles of palliative care and pain relief using opioids. Using his 25 years of experience and extensive knowledge of pain relief, he explains that he and other colleagues are trying to alleviate people’s fears of cancer by raising public awareness, through TV and articles in journals and newspapers, of the effectiveness of opioids in relieving cancer pain. He is also organizing a campaign to educate physicians about the safety and efficacy of using opioids.

### Gulhane Military Academy (GATA), Ankara

Dr. Seref Komurçu, who trained as a fellow in palliative care at the Cleveland Clinic (Ohio, US), is now teaching palliative care to colleagues in his oncology unit.

## ETHICAL ISSUES

There are three key ethical issues relating to palliative and end-of-life care in Turkey: difficulties around disclosure of prognosis that arise because the Turkish people tend to avoid openly discussing diagnosis and the progress of their illness; problems of communication with patients at the end of life and acceptance by the medical professionals; and fears about use of opioids, that can lead to low usage and potentially increased suffering at the end of life.

In terms of issues around disclosure of diagnosis and problems of communication there is a strong ethos in Turkey of keeping a diagnosis from the patient, largely because a cancer diagnosis, in particular, is still regarded as a death sentence. Also, Turkish culture has tended towards a paternalistic attitude in the physician. There are signs that physicians’ and public attitudes are changing, along with changes in legal responsibility towards patients’ rights and autonomy; these changes are essential in order to encourage a greater openness. Deniz Yamaç, medical oncologist, explains:

“Turkey is a little different from Europe, people know about end of life but they don’t say it, about half can talk about it, about cancer, but some don’t want [to hear] the name of cancer. You can act according to the patient which is in front of you. You must feel it; you must have the information before you and be open. I ask my patients, ‘What do you know about your disease, your illness, what do you need?’ So I can see my way how to act, how to talk, but I don’t think that all Turkish doctors [who] are concerned with cancer know that, so I do the workshops in communication. Not to know—how to tell. They [the patients] should know. It’s their life. I try to tell it but not to break their heart. They must know their future. But doctors run away in order to prevent themselves from hurting. Doctors are afraid of palliative care and [often] don’t want to be involved.” (22)

Oguz et al. suggest that an important ethical issue is a lack of acceptance of the end of life by health care professionals, which requires the creation of a “treatment philosophy” that acknowledges and provides for the needs of people at the end of life:

“To create this new treatment philosophy, Turkish physicians will have to accept death and dying patients as a natural life process for which medicine in its caring and comforting role has an important role.” (1)

There are ethical concerns about the continuing widespread fear of opioids, a fear which pervades the perceptions and practice of the public at the end of life and the health care

professionals who care for them. The problem about the practice of euthanasia and assisted suicide of people suffering severe under-treated pain has fuelled considerable debate in medical ethics since the mid-1970s. The point is made that improved training would result in better pain management and thus mean less suffering and consequently less call for euthanasia and assisted suicide. For example, in 2003 Turkish oncologists at Akdeniz University Hospital demonstrated a significant improvement in quality of life for cancer patients who were receiving opioids. There is a strong ethical dimension to the national campaign conducted by Serdar Erdine to educate both the public and health care professionals about the efficacy of appropriate opioid usage in alleviating cancer pain (3).

## HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

### Narrative history of palliative care

Since the mid-1990s there has been a growing awareness for the need to develop a palliative care service in Turkey that would include not only pain relief and symptom control but also the psychosocial needs of the patients, and their families, at the end of life. Traditionally, Turkish people have tended to die at home cared for by their family. In less populated rural areas home is still the commonest place of death. Studies conducted in the late 1990s and early 2000s revealed a radical shift in the place of death for Turkish people, particularly those who have migrated to urban areas, where 75% of the population now live (1,27). With this change in socioeconomic patterns, fewer women are available to care for relatives in the home. Over 60% of urban deaths are now in hospitals, although, according to one national survey of people's attitudes to dying in hospice or hospital, 47% of the 200 adults questioned would prefer to care for their dying relative at home; conversely, for themselves, 54% would prefer to die in hospital as they hoped to have better care.

Given this socio-economic and cultural background, the concepts of palliative care have proved slow to disseminate, in contrast to the development of improved methods of pain relief. Professor Serdar Erdine, Chair of the Department of Algology at Istanbul Hospital Faculty of Medicine, explains that although "the real palliative care services are very weak here, pain management is very well-developed and is going to be a specialty very soon." (3)

Political events, particularly in the 1990s, inadvertently raised awareness of the need to address adequate provision of care at the end of life, when separatist insurgency led to people fleeing from rural to urban areas (chiefly

in regions such as Diyarbakir and Adana in southeastern Turkey). This caused an enormous burden for local hospitals that were unprepared for such a large increase in their patient populations and, most significantly, the consequent increase in the need for narcotic drugs for patients at the end of life.

Several pain specialists and oncologists have recognized the need for specialist palliative care services since the mid-1990s, and a number have sought palliative medicine training overseas and returned to encourage training and development within their own units and faculty departments. There are, however, no national guidelines or government-financed support for palliative care services, although a cancer control policy is being prepared and there is now a public health policy for AIDS. Most of the interested oncologists and pain specialists are working in relatively few university hospitals (there are a total of 50 government-supported university hospitals in the country and 668 government-funded Ministry of Health hospitals). In 2003, Professor Yasemin Oguz, of the Unit of Deontology (Medical Ethics) in the Faculty of Medicine at Ankara University co-authored a paper with colleagues in which they report that end-of-life care services continue to be markedly inadequate. In particular, she and her colleagues highlight the lack of nursing or financial support for families who have to care for their older, terminally ill relatives at home, which increases the likelihood of hospital admission. Oguz et al. (1) note the issues around using opioids, points reiterated by Serdar Erdine in 2005, and suggest that too often the end of life is likely to be painful and lonely in the hospital.

A needs assessment was due to be conducted by Professor Oguz in 2004 because as she describes, a major problem in meeting the palliative care needs of patients and educating health care professionals lies in the lack of data:

"As the Director of the needs assessment project for palliative care in Turkey I may say that our main problem is the lack of national data on the subject. Without essential data it is not possible to convince the Turkish Ministry of Health and National Health Insurance Organizations about the importance of the subject. Palliative care and end-of-life issues are a kind of no man's land in Turkey. Although many health care professionals encounter the problems and are aware of the need, they do not see the subject as their business. There are financial and legal restrictions. Our initial objective is to establish a continuous communication between interested professionals and patient advocacy groups. There are a couple of nongovernmental organizations which may support the efforts. One of them is the Association of Patients with Cancer. Their main concern is financial problems of cancer pa-

tients. Another important group is the Turkish Oncology Group which is not a formal association, but a collection of interested professionals. It has a subgroup named Education, Research and Supportive Treatments.” (16)

Unfortunately, the palliative care needs assessment described here has been delayed for lack of funds (14). Although these economic difficulties are reported to act to slow the development of hospice home care, there are some recent initiatives, driven by members of the Turkish Oncology Group. For example, medical oncologists Dr. Perran Fulden Yumuk and Dr. Nazim Turdal at the Marmara University Medical School Hospital in Istanbul report:

“We are planning to build a hospice and one fellow is being educated in USA for this purpose and she will finish her fellowship in three years. At this time there are no university- or government-based hospice programs in Istanbul. Most of the time patients are admitted to hospitals for palliative support, which is usually unnecessary use of beds, etc. This is why we decided to build a hospice in Istanbul.” (10)

There are also plans to build an inpatient hospice at the Hacettepe Hospital in Ankara. This is a project initiated and encouraged by Professor Dincar Firat, President of the Turkish Oncology Group. Members of the Turkish Oncology Group (TOG) have also been active in encouraging the development of palliative care training. As part of this initiative to raise awareness and address the need for palliative care, the TOG organized a conference in Istanbul during October 2004, dedicated to developing home-based palliative care programs. Dr. Seref Komurçu reported:

“After that meeting we invited some people from government and from insurance companies, so they learned something about home care programs and the need for the programs. So I believe that meeting helped a lot, and there were some discussions about the new regulations on home care, and I think three weeks ago regulations were done. The government asks our Society about home care, how it can be controlled and to what standard. We gave some opinions, and the government also took some other ideas from some other organizations.” (6)

Although the Turkish Oncology Group has supported the concept of palliative medicine for medical oncologists and other interested health care professionals, professional oncology nursing organizations are not yet involved in developing specialist palliative care training.

In June 2004, Turkey joined the Middle East Cancer Consortium (MECC). Funded by the National Cancer Institute (Bethesda, Maryland, USA), the organization is involved in helping its six member countries to develop a standardized cancer registry as part of its goal to raise cancer awareness and reduce the burden of cancer in the region. MECC organizes and offers free places at its seminars and conferences for its member countries' health care professionals. From February 2004, MECC has been supporting initiatives to assess palliative care provision, needs and training.

## LIFE/ORAL HISTORIES

**Dr. Seref Komurçu--Medical Oncologist, Gulhane Military Academy:** *interviewed by Amanda Bingley--18 April 2005--duration of interview: 35 minutes*

Seref Komurçu talks about his education as a fellow in the US at the Cleveland Clinic and also in the Palliative Care Department. Since his return eight years ago he has been developing and teaching palliative care in his oncology unit.

**Dr. Deniz Yamaç--Associate Professor of Internal Medicine and Medical Oncology, Gazi University Hospital:** *interviewed by Amanda Bingley, 6 July 2005--duration of interview: 45 minutes*

Deniz Yamaç, who specializes in breast cancer and head and neck cancer, talks about her growing interest in palliative care, since 1995, following her training in medical oncology at Arkansas Cancer Institute (Arkansas, USA). She explains that after some years in oncology, she realized she had to know about palliative care and set about studying on her own. She offers palliation to her own patients at the end of life, and advises colleagues about palliation for their patients. She is actively developing palliative care training in the oncology unit, and with medical students in the university medical school. She is taking part in a project to train general nurses in home care.

**Professor Serdar Erdine--Chair of Algology, Istanbul University Faculty of Medicine:** *interviewed by Amanda Bingley, 11 July 2005--duration of interview: 36 minutes*

Serdar Erdine talks about his work developing pain management and seeing a pain or algology specialty recognized.

He also describes the current attitudes towards palliation in Turkey, and his campaign to raise public awareness of the efficacy of cancer pain relief, to alleviate fears of opioids, and to educate physicians in opioid use.

## REFERENCES

[www.who.int/cancer/palliative/en/](http://www.who.int/cancer/palliative/en/)

Center for Bioethics. End of life care: an ethical overview. University of Minnesota [www.bioethics.umn.edu/publications/End\\_of\\_Life.pdf](http://www.bioethics.umn.edu/publications/End_of_Life.pdf), 2005.

Erdine S. Turkey: status of cancer pain and palliative care, *Journal of Pain and Symptom Management*, 1996;12:2,139-40.

Erdine S. Education and sub-specialization in pain medicine, paper given at "The Global Day against Pain," Geneva, Switzerland - 11 October 2004 [www.efic.org/2005news.htm](http://www.efic.org/2005news.htm). 2004.

Gozum S, Tezel A, Koc M. Complementary alternative treatments used by patients with cancer in eastern Turkey, *Cancer Nursing*. 2003;26:3,230-236.

Livneh J, Garber A, & Shaevich E. Assessment and documentation of pain in oncology patients. *International Journal of Palliative Nursing* 1998;4:4,169-175.

Oguz NY. Narrativity in bioethics: with special reference to medical ethics, *Eubios Journal of Asian and International Bioethics* 1999;9:130-134.

Oguz NY, Miles SH, Buken N, Civaner M. End of life care in Turkey, *Cambridge Quarterly of Healthcare Ethics*, 2003;12,279-284.

Ott BB, Al-Khadhuri J, Al-Junaibi S. Preventing ethical dilemmas: understanding Islamic health care practices. *Pediatric Nursing*, 2003;29:3,227-230.

Savas BS, Karahan O, Saka RO. In: Thomson S & Mossialos E, eds. *Health care systems in transition: Turkey*. Copenhagen: European Observatory on Health Care Systems, 2002;4. [www.euro.who.int/document/E79838.pdf](http://www.euro.who.int/document/E79838.pdf).

Stjernswärd J, Clark D. Palliative medicine--a global perspective. In: Doyle D, Hanks G, Cherny N, Calman K (eds.). *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 2003.

Turdal NS, Efe B, Gumus M, Aliustaoglu M, Karamanoglu A, Sengov M. Patient satisfaction in the outpatients' chemotherapy unit of Marmara University, Istanbul, Turkey: a staff survey *BMC Cancer*, 2002;2:30 [www.biomedcentral.com/1471-2407/2/30](http://www.biomedcentral.com/1471-2407/2/30).

2. Questionnaire from International Palliative Care Initiative, Open Society Institute, New York: respondent--Dr. Sevin Baser, Pulmonary Specialist and Assistant Professor, Pamukkale University Medical School--2 November 2004
3. IOELC interview: Professor Serdar Erdine--11 July 2005
4. [baskent-izm.edu.tr](http://baskent-izm.edu.tr)
5. Eoin Tiernan. Turkish Oncology Group website report on International Interim Meeting on Home Care and Hospice in Oncology, 7-9 October 2004, Istanbul, Turkey. [www.mascc.org/kml2/images/uploads/Articles\\_ContentDocs/Report\\_on%20Istanbul%5B1%5D.Tiernan11.04.doc](http://www.mascc.org/kml2/images/uploads/Articles_ContentDocs/Report_on%20Istanbul%5B1%5D.Tiernan11.04.doc)
6. IOELC interview: Dr. Seref Komurcu--18 April 2005
7. COPD = Chronic Obstructive Pulmonary Disease
8. IOELC Questionnaire: Dr. Osman Abbasoglu--5 March 2005
9. Turdal NS, Efe B, Gamus M, Aliustaoglu M, Karamanoglu A, Sengov M. Patient satisfaction in the out patients' chemotherapy unit of Marmara University, Istanbul, Turkey: a staff survey, *BMC Cancer*, 2002;2:30 [www.biomedcentral.com/1471-2407/2/30](http://www.biomedcentral.com/1471-2407/2/30)
10. IOELC questionnaire: Dr. Perran Fulden Yumuk and Dr. Nazim Serdar Turdal--20 July 2005
11. See Turkish Society of Algology [www.algoloji.org.tr](http://www.algoloji.org.tr).
12. Erdine S. Turkey: status of cancer pain and palliative care, *Journal of Pain and Symptom Management*, 1996;12:139-40.
13. WHO Cancer pain relief and palliative care: report of a WHO Expert Committee, Geneva: World Health Organization Technical Report Series: 804, 1990.
14. Email communication: Professor Yasemin Oguz--18 September 2005
15. Savas BS, Karahan O, Saka RO. In: Thomson S & Mossialos E, eds. *Health care systems in transition: Turkey*. Copenhagen: European Observatory on Health Care Systems, 2002;4. [www.euro.who.int/document/E79838.pdf](http://www.euro.who.int/document/E79838.pdf).
16. IOELC questionnaire: Professor Yasemin Oguz--31 December 2003
17. IOELC interview: Dr. Deniz Yamac--6 July 2005
18. IOELC interview: Dr. Seref Komurcu--18 April 2005
19. Savas BS, Karahan O, Saka RO. In: Thomson S. & Mossialos E, eds. *Health care systems in transition: Turkey*. Copenhagen: European Observatory on Health Care Systems, 2002;4. [www.euro.who.int/document/E79838.pdf](http://www.euro.who.int/document/E79838.pdf).
20. MASCC "The Multinational Association of Supportive Care in Cancer is an international, multi-disciplinary organization with over 1000 members representing more than thirty countries and five continents. It operates in collaboration with the International Society for Oral Oncology. Founded in 1990, this group is dedicated to research and education in all measures of supportive care for patients with cancer, regardless of the stage of the disease. MASCC aims to promote professional expertise of supportive care through research and international scientific exchange of ideas. Significant advances in cancer treatment in the last two decades have been made possible by the strides in supportive care." For more details [www.mascc.org/](http://www.mascc.org/)

## ENDNOTES

1. Oguz NY, Miles SH, Buken N, Civaner M. End of life care in Turkey, *Cambridge Quarterly of Healthcare Ethics*, 2003;12,279-284.

21. Eoin Tiernan. Turkish Oncology Group website report on International Interim Meeting on Home Care and Hospice in Oncology, 7-9 October, 2004, Istanbul, Turkey [www.mascc.org/ktml2/images/uploads/Articles\\_ContentDocs/Report\\_on%20Istanbul%5B1%5D.Tiernan11.04.doc](http://www.mascc.org/ktml2/images/uploads/Articles_ContentDocs/Report_on%20Istanbul%5B1%5D.Tiernan11.04.doc)
22. IOELC interview: Dr. Deniz Yamac--6 July 2005
23. The Turkish Code of Medical Ethics 1960 supports this attitude: "The physician must openly tell the patient the measures that should be taken in his/her situation, if it is not likely to make his/her illness worse by disturbing his/her mood, unless it seems appropriate to hide a serious prognosis." (Information supplied by Prof Yasemin Oguz, 18 September 2005.)
24. Buken NO. Truth-telling information and communication with cancer patients in Turkey, *JISHIM*, 2003;3:31-36 [www.ishim.net/ishimj/4/05.pdf](http://www.ishim.net/ishimj/4/05.pdf)
25. Aydin E. Rights of patients in developing countries: the case of Turkey, *Journal of Medical Ethics*, 2004;30:555-557
26. Arda, BB. Bioethics in Turkey, *Eubios Journal of Asian and International Bioethics*, 1995;5:64-65.
27. Oguz NY. Euthanasia in Turkey: cultural and religious perspectives, *Eubios Journal of Asian and International Bioethics*, 1996;6:170-171.
28. Aksoy S. Ethical considerations on end of life issues in Turkey, In Song KY, Koo YM, and Macer DDRJ, eds., *Bioethics in Asia in the 21st century* Eubios Ethics Institute, 2003. [www.biol.tsukuba.ac.jp/~macer/ABC4/abc4079.htm](http://www.biol.tsukuba.ac.jp/~macer/ABC4/abc4079.htm)
29. Bozcuk H, Kolagasi O, Samur M, Yıldız M, Ozdogan M, Artac M, Savas B. A brief information sheet on opioid effects improves quality of life in cancer patients on opioids, *The Internet Journal of Pain, Symptom Control and Palliative Care*, 2003;2:2 [www.ispub.com/ostia/index.php?xmlPrinter=true&xmlFilePath=journals/ijps/vol2n2/opioids.xml](http://www.ispub.com/ostia/index.php?xmlPrinter=true&xmlFilePath=journals/ijps/vol2n2/opioids.xml)
30. Aksoy S. Ethical considerations on end of life issues in Turkey, In Song KY, Koo YM, and Macer DRJ eds. *Bioethics in Asia in the 21st century* (Eubios Ethics Institute), 2003, [www.biol.tsukuba.ac.jp/~macer/ABC4/abc4079.htm](http://www.biol.tsukuba.ac.jp/~macer/ABC4/abc4079.htm) (see also Arda B, Evaluation of research ethics committees in Turkey, *Journal of Medical Ethics* 2000;26:459-461.)
31. Ozyalcin NS, Talu GK, Camlica H, Erdine S. Efficacy of celiac plexus and splanchnic nerve blockades in body and tail located pancreatic cancer pain, *European Journal of Pain*, 2004;8:539-545.
32. Email communication: Professor Yasemin Oguz--4 August 2005
33. IOELC questionnaire: Professor Yasemin Oguz--31 December 2003
34. Email communication: Dr. Eoin Tiernan--10 March 2005
35. Kav S. Cancer Nursing Education in Turkey, Report for ISNCC--International Society of Nurses in Cancer Care, 2005. [www.isncc.org/about/](http://www.isncc.org/about/) (Sultan Kav is an oncology nursing educator at Hacettepe University Hospital and a member of the Turkish Oncology Nurses Association)
36. National Cancer Bulletin: Eliminating the suffering and death due to cancer. Special Issue National Cancer Institute 2004;1:43, November 9 [www.cancer.gov](http://www.cancer.gov)



# Appendix 1

## Example of the IOELC questionnaire sent to participants for MECC country report project 2005

International Observatory on End of Life Care

### PALLIATIVE CARE IN (Name of country)

1 Name of your organization \_\_\_\_\_

2 Address \_\_\_\_\_

3 Telephone \_\_\_\_\_ 4 Email \_\_\_\_\_

6 What date was your organization established? \_\_\_\_\_

7 Why did it begin? \_\_\_\_\_

What types of service are provided?

Please tick as appropriate

#### 8 ADULT

Home care \_\_\_\_\_

Inpatient care \_\_\_\_\_

Day care \_\_\_\_\_

Clinic/ Drop-in Center \_\_\_\_\_

Hospital support team \_\_\_\_\_

Other \_\_\_\_\_

If other, please state: \_\_\_\_\_

\_\_\_\_\_

#### 9 PEDIATRIC

Home care \_\_\_\_\_

Inpatient care \_\_\_\_\_

Day care \_\_\_\_\_

Clinic/ Drop-in Center \_\_\_\_\_

Hospital support team \_\_\_\_\_

Other \_\_\_\_\_

If other, please state: \_\_\_\_\_

\_\_\_\_\_

10 How many staff work for the organization i) full-time \_\_\_\_\_ ii) part-time \_\_\_\_\_

11 Number of staff by role i) doctor \_\_\_\_\_ ii) nurse \_\_\_\_\_ iii) chaplain \_\_\_\_\_  
iv) counsellor \_\_\_\_\_ v) social worker \_\_\_\_\_ vi) educator \_\_\_\_\_ vi) pharmacist \_\_\_\_\_  
viii) administrator \_\_\_\_\_ ix) fundraiser \_\_\_\_\_ x) volunteer \_\_\_\_\_

12 How are your staff trained? \_\_\_\_\_  
\_\_\_\_\_

13 How many patients did your service care for during 2003? \_\_\_\_\_

14 What drugs are used for pain relief? \_\_\_\_\_  
\_\_\_\_\_

15 How are these drugs prescribed and administered? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

16 What are the three major challenges facing palliative care development at present?  
i)  
ii)  
iii)

17 What are the three major opportunities for palliative care development?  
i)  
ii)  
iii)

18 What are the ethical issues facing palliative care in South Africa?

19 What are the key successes of your service?

20 Any other information you would like to add?

Your name \_\_\_\_\_ Your role \_\_\_\_\_

Thank you for your help; it is very much appreciated.

Amanda Bingley: International Observatory on End of Life Care, IHR Lancaster  
University, UK. March 2005

# Appendix 2

## IOELC interview template as used for MECC country report project 2005

### Interviews: general guidelines

#### Generic questions

This is a broad list of generic questions. It's sometimes not possible to include all of these, especially if supplementary questions are asked, but these are the main areas.

- 1 How did you come to be involved in palliative care?
- 2 When did your service begin and why? Who were the main activists? What area does the service cover?
- 3 In what sense is your service a hospice/palliative care organization?
- 4 How many nurses/doctors/administrators/volunteers other staff are associated with your service? How many work full-time/part-time for the organization?
- 5 What training programs are associated with your service?
- 6 How are patients referred to you?
7. What drugs do you use for pain relief? Who prescribes them?
- 8 How accessible is morphine? How are prescriptions written and supplied? What regulations govern the use/supply of morphine?
- 9 What provision is made for the spiritual dimension of palliative care? Who gives spiritual care? What does spirituality mean to the patients?
- 10 How many patients does your service care for each year? What are the most common diseases?
- 11 What are the major ethical issues facing the service at present?
- 12 What successes have been achieved so far?
- 13 What does the service need now?
- 14 What are your priorities for the future?



# Appendix 3

## Comparison of the political economies of Cyprus, Egypt, Israel, Jordan, Palestinian Authority, and Turkey

The MECC region members have widely differing economies (Table A). These range from the high per capita Gross Domestic Product (GDP) of Israel (Intl \$22,731) and Cyprus (Intl \$15,602) to the poorer economies of Turkey (Intl \$7,688), Jordan (Intl \$4,947), Egypt (Intl \$4,274) and resource-poor Palestinian Authority (West Bank Intl \$1,100, Gaza Strip Intl \$600).

**Table A: GDP per capita (Intl \$): MECC members 2006 \***

Country/Area	GDP per capita (Intl \$)
Israel	22,731
Cyprus	15,602
Turkey	7,688
Jordan	4,947
Egypt	4,274
Palestinian Authority West Bank	1,100
Palestinian Authority Gaza Strip	600

*Source: WHO report (2006) \* Figures refer to 2004 data with the exception of Jordan which refers to 2003*

The disparity between the economies of MECC members is reflected in their different capacities to support adequate resources for health care services, which, as discussed in Chapter 2, tends to impact on the resources available to fund hospice and palliative care services. Two long-running political and military conflicts also beset the region. The internationally recognized Greek Cypriot south and the unrecognized Turkish north of the island of Cyprus have been in conflict for over 40 years. Israel and the Palestinian Authority (occupied Palestinian Territories) have been embroiled in conflict over the last six decades which seriously disrupts political life and the economies of both communities. The intensification of events since 2000 has severely interfered with the capacity of the Palestinian Authority to provide social and health care in the occupied Palestinian Territories. The Israeli/Palestinian conflict also has led at different times to conflict with Jordan and Egypt.

Increasing tourism tends to boost the economy in Cyprus, Turkey and Egypt, despite political instability continuing to put a strain on the socioeconomic resources of the region. The political economy of Jordan is reasonably stable, and the ruling Hashemite Kingdom of Jordan under King Abdullah is committed to maintaining and developing adequate social and health care programs. Although Egypt is a relatively stable regime, various complex socio-economic and population pressures result in significant levels of poverty and inequalities in health care provision across the country. The political background to individual MECC member countries and the Palestinian Authority are briefly summarized below:

### CYPRUS

A former British colony, Cyprus gained independence in 1960 as the United Nations (UN)-recognized Republic of Cyprus. The island has been divided since 1974 when continuing conflicts between the Greek Cypriot majority and the Turkish Cypriot minority culminated in a Turkish military invasion. The United Nations was asked to intervene and subsequently UN peacekeeping forces established a buffer zone known as the “Green Line,” which still separates the two ethnic communities inhabiting the island (Greek Cypriots in the south and Turkish Cypriots in the north). This separation dominates Cypriot life and has a significant impact on provision of health services in the two communities. In 1983 Turkish Cypriots in the north declared independence and formed a “Turkish Republic of Northern Cyprus” (TRNC), recognized only by Turkey. Since 2003 greater access has been agreed between the two areas. The internationally-recognized Greek Cypriot Republic of Cyprus in the south is now a member of the European Union having joined in May 2004. Now every Cypriot carrying a Cyprus passport has the status of a European citizen. There are no direct trade and economic links between the Greek Cypriot south and the Turkish Cypriot north. The south, however, is considerably more prosperous, supported in part by relatively high revenues from a successful and growing tourist industry, agricultural exports, and the development of positive trade and

economic links in Europe. At the time of writing, talks between two communities, brokered by the UN, have failed to agree on a unity plan.<sup>1</sup>

## EGYPT

The Arab Republic of Egypt is a largely desert country, bisected by the highly fertile Nile valley, home to 99% of the population and the site of most economic activity. The Egyptian government inherited a highly centralized economy from President Nasser 30 years ago. Since 1981, led by President Mubarak, the government has worked towards economic reform to create a decentralized, mainly privatized system. The process has been slow, given growing population pressure on extremely limited agricultural and land resources combined with very little foreign direct investment. Egypt is no longer self-sufficient in food, and imports nearly half its foodstuffs. Low annual GDP growth has resulted in considerable economic problems that deepened from the mid-1990s. In 2003, Egyptian officials increased subsidies on basic foodstuffs to placate public unrest but this worsened existing budget deficits, despite good revenues from tourism and the Suez Canal. In 2005, Prime Minister Ahmed Nazif reduced tax rates and energy subsidies, and privatized some government enterprises, which increased the GDP. These policies, though, have not made any substantial improvement in living standards for the average Egyptian. The government has to provide subsidies for basic necessities and also runs a “Social Fund for Development” to support the poorest sector by subsidizing community infrastructure and services, and supporting small businesses.<sup>2</sup>

## ISRAEL

The political economy of Israel is heavily affected by historical events and conflicts, which have continued since the end of WW2, when the British withdrew from their mandate of Palestine, and the UN partitioned the area into Arab and Jewish states. The Israelis defeated the Palestinian Arabs in a series of wars without ending the deep tensions between the two sides. In 1993, Israeli and Palestinian officials signed a Declaration of Principles (the “Oslo accords”) guiding an interim period of Palestinian self-rule. Outstanding territorial and other disputes with Jordan were resolved in the 1994 Israel-Jordan Treaty of Peace. In May 2000, Israel withdrew unilaterally from southern Lebanon, which it had occupied since 1982, but hostilities recurred in July 2006 leading to a second Israeli invasion of southern Lebanon. In September 2006 a ceasefire agreement was reached with the intervention of international peacekeeping forces. Since September 2000, international efforts to encourage a permanent status

agreement with the Palestinian Authority have failed in the face of ongoing violent conflicts. Following the death of Yassir Arafat, a new Palestinian leader, Mahmoud Abbas was elected in January 2005. This coincided with the formation of a Likud-Labor-United Torah Judaism coalition government in January 2005, and the successful Israeli disengagement from the Gaza Strip (August-September 2005), which presented an opportunity for a renewed peace effort.<sup>3</sup> In 2006, internal Israeli and Palestinian political events further destabilized the political situation into another bitter phase of conflict.

Despite limited natural resources, Israel has intensively developed agricultural and industrial sectors. Importing substantial quantities of grain, the country is largely self-sufficient. Despite using advanced irrigation and agricultural methods, Israel has limits on water supplies and few energy resources, and is completely dependent on foreign supplies of oil, coal and gas. The US is Israel’s major source of economic and military aid. In the 2000s, adverse effects of the Israeli-Palestinian conflict together with difficulties in the high-technology, construction, and tourist sectors have resulted in relatively wide fluctuations in GDP, around a third of which funds defense. The Israeli government maintains a strong commitment to supporting basic social, health care and educational needs in the population.<sup>4</sup>

## JORDAN

Jordan gained independence from British administration in 1946, since when the country has been ruled by the Hashemite Kingdom. King Hussein ruled from 1953 until his death in 1999, when he was succeeded by his eldest son King Abdullah II. A pragmatic ruler, King Hussein successfully navigated competing pressures from the major powers of the day (US, USSR, and UK), various Arab states, Israel, and a large internal Palestinian population despite several wars and coup attempts. In 1989 he re-instituted parliamentary elections and gradual political liberalization; in 1994 he signed a formal peace treaty with Israel. King Abdullah has continued with political reforms and has instigated progressive reforms in the economy and health care system. Parliamentary and municipal elections took place in the summer of 2003. In December 2005 the newly elected government declared its commitment to accelerated economic and political reforms and the new cabinet includes an unprecedented four women as ministers.<sup>3</sup> Jordan has limited supplies of water and other natural resources such as oil. Debt, poverty, and unemployment are significant problems. Since 1999, King Abdullah has undertaken some broad economic reforms in a long-term effort to improve living standards, by improving productivity and foreign investment. Jordan imported most of its oil from Iraq,

but the US-led war in Iraq in 2003 made Jordan more dependent on oil from other Gulf nations, forcing the Jordanian Government to raise retail petroleum product prices and the sales tax base. Jordan's export market, which is heavily dependent on exports to Iraq, was also affected by the war.<sup>3</sup>

## PALESTINIAN AUTHORITY

The occupied Palestinian Territory has a long history of conflict dating back to the end of the Ottoman Empire during WW1, after which Palestine was under British mandate until 1947. At the end of WW2 the UN negotiated partition of Palestine to create the independent State of Israel in 1948; this resulted in the 1948 war when Israel expanded into 77% of existing Palestinian territory, including a large part of Jerusalem, causing over half the indigenous population to flee or be expelled. In the 1967 war Israel secured the remaining territories (Gaza Strip, the West Bank and East Jerusalem) from Jordanian and Egyptian control and a further estimated half a million Palestinians fled to neighboring countries.<sup>5</sup> In 1987, following 20 years of failed attempts by the UN and the international community to resolve the conflict, a mass uprising of Palestinians marked the first “intifada,” but led to heavy Israeli reprisals. From 1991, proposals to bring about a peaceful resolution to the conflict were made by the UN and supporting countries, culminating in 1993 with the signing of the Israel-PLO Declaration of Principles on Interim Self-Government Arrangements (the DOP). This agreement allowed an elected Palestinian Authority to self-govern the Gaza Strip and the West Bank. In successive years until 1999 negotiations between the Palestinian Authority and Israel Gaza Strip aimed to secure permanent agreements about transferring powers and responsibilities to the PA for additional areas in Gaza and the West Bank. This process was disrupted by new waves of conflict arising from the second “intifada” in September 2000. In April 2003 the US, EU, UN, and Russia presented a “roadmap” to a final settlement of the conflict by 2005 based on reciprocal steps by the two parties leading to two states, Israel and a democratic Palestine. The proposed date for a permanent status agreement has been postponed indefinitely due to violence and accusations that both sides have not followed through on their commitments.<sup>3</sup> Mahmoud Abbas was elected Palestinian president in January 2005, bringing hope of a turning point in the conflict. During August and September 2005, Israel withdrew all its settlers and soldiers and dismantled its military facilities in the Gaza Strip and four northern West Bank settlements, retaining controls over maritime, airspace, and most access to the Gaza Strip. Another bitter round of hostilities erupted in 2006 following the

Palestinian election of the Hamas government, leading to fierce fighting and Israeli reprisals in the Gaza Strip. At the time of writing there are renewed attempts to maintain a ceasefire and start new negotiations towards a peaceful resolution.<sup>3</sup>

The beginning of the second “intifada” in September 2000 sparked an economic downturn, largely the result of Israeli closure policies which were imposed in response to security interests, but disrupted labor and commodity relationships with the Gaza Strip. In 2001, and even more severely in 2003, Israeli military action in Palestinian areas resulted in the destruction of much capital plant, the disruption of administrative structure, and widespread business closures. The UN estimates that over 100,000 Palestinians out of the 125,000 in Gaza and the West Bank, who used to work in Israel or in joint industrial zones, have lost their jobs. Half the labor force is unemployed. In the West Bank, high unemployment and limited trade opportunities, due to continued closures both within the West Bank and externally, continues to stem economic growth.<sup>3</sup> The Israeli withdrawal from the Gaza Strip in September 2005 initially offered some medium-term opportunities for economic growth, especially given the removal of restrictions on internal movement. Agreements and continuing negotiations on the administration of Gaza's border crossings increased the prospects for trade. In 2006, renewed conflict with Israel and internal political instability has led to the reinstatement of tough border restrictions and an escalating humanitarian crisis in Gaza.<sup>6</sup>

## TURKEY

The modern state of Turkey was founded in 1923 by national hero Mustafa Kemal (known as Atatürk, or “Father of the Turks”), following the defeat of the Ottoman Empire. After a period of one-party rule, an experiment with multi-party politics led to the 1950 election victory of the opposition Democratic Party and the peaceful transfer of power. Since then, Turkish political parties have multiplied, but democracy has been fractured by periods of instability and intermittent military coups (1960, 1971, 1980), which in each case eventually resulted in a return of political power to civilians. In 1997, the military again helped engineer the ouster--popularly dubbed a “post-modern coup”--of the then Islamic-oriented government. Turkey has been in conflict with Cyprus since 1974 when it intervened militarily to prevent a Greek takeover of the island and now acts as patron state to the “Turkish Republic of Northern Cyprus,” (TRNC) which only Turkey recognizes. Since 1984 an ongoing military conflict between the Turkish government and Kurdish separat-

ist insurgency--now known as the People's Congress of Kurdistan or Kongra-Gel (KGK)--has claimed more than 30,000 lives. After the capture of the group's leader in 1999, the insurgents largely withdrew from Turkey, mainly to northern Iraq. In 2004, KGK announced an end to its ceasefire and attacks attributed to the KGK increased. Turkey joined the UN in 1945 and in 1952 it became a member of NATO. In 1964, Turkey became an associate member of the European Community; over the past decade, it has undertaken many reforms to strengthen its democracy and economy, enabling it to begin accession membership talks with the European Union.<sup>3</sup>

Turkey has a strong traditional agriculture sector that accounts for more than 35% of employment, along with a very active industrial base. The economy is turning around with the implementation of economic reforms, and 2004 GDP growth reached 9%. Inflation fell to 7.7% in 2005--a 30-year low. Further economic and judicial reforms and prospective EU membership may encourage foreign investment. The state still plays a major role in basic industry, banking, transport, and communication, although the private sector is strong and growing. The government is committed to supporting basic social care, health care and education.

6. WHO Health Crisis in Action Report, July 2006 access on weblink [http://millenniumindicators.un.org/unsd/mi/mi\\_results.asp?crID=275&fID=r15](http://millenniumindicators.un.org/unsd/mi/mi_results.asp?crID=275&fID=r15)

## ENDNOTES

1. This is a précised account of the history of conflict and the ongoing negotiations towards a peaceful resolution between the Greek Cypriots in the south of the island and Turkish Cypriots in the north. See United Nations Peacekeeping Mission in Cyprus UNFICYP website. More details can be found on the UN website:  
<http://www.un.org/Depts/dpko/missions/unficyp/index.html>.  
Also see World Factbook:  
<http://www.cia.gov/cia/publications/factbook/geos/cy.html>
2. See the United Nations [http://www.uneca.org/aisi/nici/country\\_profiles/Egypt/egyptab.htm](http://www.uneca.org/aisi/nici/country_profiles/Egypt/egyptab.htm) and the World Factbook <https://www.cia.gov/cia/publications/factbook/geos/eg.html> for sources of this summary and more details of the political economy of Egypt.
3. Parts of this citation are précised from the World Factbook entry accessed 10 October 2006  
<https://www.cia.gov/cia/publications/factbook/geos/is.html>
4. See the United Nations [http://www.unodc.org/egypt/en/country\\_profile\\_israel.html](http://www.unodc.org/egypt/en/country_profile_israel.html) and the World Factbook <https://www.cia.gov/cia/publications/factbook/geos/eg.html> for sources of this summary and more details of the political economy of Israel.
5. For an overview of Palestinian history see the UN website <http://www.un.org/Depts/dpa/qpalnew/overview.htm>





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