Culturally Competent

# Caregiver Support Programs

*A Practical Guide for Service Providers*

## Cuidando con Confianza
## *Caring with Confidence*

Pima Council on Aging
Tucson, Arizona

# CULTURALLY COMPETENT

# CAREGIVER SUPPORT PROGRAMS

## A PRACTICAL GUIDE FOR SERVICE PROVIDERS

**ACKNOWLEDGEMENTS**
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South Tucson City Council
South Tucson Police Department
South Tucson Fire Department
South Tucson Weed and Seed Program
John Valenzuela Youth Center
House of Neighborly Services
Project Y.E.S.
South Tucson Housing Authority
COPE Behavioral Services, Inc.
University of Arizona, Center on Aging
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Lily Alvarez

# PIMA COUNCIL ON AGING

**The Pima Council on Aging (PCOA)**, first established in 1967, is a private non-profit corporation that has served as the Area Agency on Aging for Pima County, Arizona since 1973. PCOA serves as advocate, planner, coordinator, developer, and provider of services. As the Area Agency, PCOA is responsible for developing support services to assist elderly persons to remain independent in their homes and communities. Under the Administration on Aging, National Family Caregiver Support Program, PCOA is also responsible for additional services to assist caregivers.

PCOA contracts with community agencies to provide congregate and home-delivered meals, case management, personal care, housekeeping, electronic emergency alert, major and minor home repair, respite, transportation, community nursing, and legal services. Direct services include family caregiver information and assistance, ombudsman services, personal budgeting assistance, Medicare insurance counseling, minority and rural benefits/outreach staff and Retired Senior Volunteer Program. Among the strong community relationships, PCOA works closely with many of the local caregiver programs and services including the Mature Worker Employment Program, the Neighbors Care Alliance and Ambassador Programs, the county's Caregiver Education and Support Program, Senior Resource Network, the Alzheimer's Association, the American Parkinson's Disease Association, the Arthritis Foundation, the Parish Nurse Network, and the Caregiver Consortium, to name a few.

PCOA's years of experience, in-house expertise, and community relationships provide for an expedient identification of gaps in caregiver services, the development of strategies for meeting the identified needs, and the administration of contracts with community agencies to deliver the requested services.

FOR MORE INFORMATION

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# Preface

# PREFACE

Cuidando con Confianza was initiated in 2001 as a demonstration project to determine the best methods of providing caregiver support to culturally diverse populations. This project was conducted over three years in the City of South Tucson, Arizona, with a population of Mexican American caregivers. The project was funded by the U.S. Department of Health and Human Services, Administration on Aging, National Family Caregiver Support Programs, as an Innovative Program of National Significance. Additional support was provided through in-kind services provided by the Pima Council on Aging, the City of South Tucson, COPE Behavioral Services, and the University of Arizona Center on Aging.

By sharing the experiences and knowledge gained on this project, we hope to help service providers develop culturally competent caregiver support programs. We feel that the design and methodologies utilized on this project can be adapted for other ethnic populations.

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This project is supported, in part, by a grant, number 90CG2534, from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

# Introduction

# INTRODUCTION

Policymakers must be challenged to determine caregiver needs and design supportive services tailored to meeting those needs. Planners of human service programs, along with stakeholders, must identify the special needs of the community to be served. Programs must be developed in a manner that complements and is sensitive to the cultural norms and life experience of those consumers. This is especially important in Latino communities, as the elderly Latino population is now the fastest growing elderly population in the United States (Hooyman and Kiyak, 1999).

The Pima Council on Aging, the Area Agency on Aging in Tucson, Arizona, undertook this demonstration to develop, test and implement an effective, culturally appropriate, and acceptable family caregiver support model. Project partners included the residents and the City of South Tucson, COPE Behavioral Services, Inc., and the University of Arizona Center on Aging. The project utilized a collaboration in which local caregivers and community members developed a model responsive to the specific needs of the South Tucson populations. The South Tucson community is 90% minority, mainly Mexican American, with a significant percentage of multigenerational, multiple caregiver networks. The project addressed the need to devise culturally appropriate methods to alleviate the stress and burden experienced by primary caregivers.

When attempting to address the needs of culturally defined populations, social and human service "interventions" fail when providers do not become knowledgeable about the community in terms of its economic conditions, political structures, cultural norms and values, demographic trends, history, and experience with previous intervention efforts. Well-meaning "outsiders," often assume the role of "expert," and tell service "recipients" what they need and how programs will be implemented.

Partnering with the community is necessary to improve health outcomes and create positive change. Rather than being defined as the " target recipients" of services, these community members must be recognized as the "resource" that ensures the success of the programs. This guide will provide the steps taken to implement a caregiver support program that was defined by the community members. As a community empowerment model, the methods used can be adapted and used for other ethnic populations.

**Those individuals whose lives are defined by the culture must define their own needs and the cultural and community assets that can be mobilized to sustain a collaborative program.**

# Project Partners

## PROJECT PARTNERS

The citizens of South Tucson, in conjunction with PCOA, developed and implemented Cuidando con Confianza with support from additional project partners including the City of South Tucson, COPE Behavioral Services, Inc., and the University of Arizona, Center on Aging.

**The City of South Tucson** is a predominantly Mexican American community striving to maintain its rich ethnic heritage and traditions amid the many social and economic pressures that affect low income, minority neighborhoods. The City is slightly larger than one square mile, located in Pima County, Arizona, approximately 65 miles from the Mexican-American border, and bounded on all sides by the greater Tucson metropolitan area. Located adjacent to the Tucson downtown area, the City faces many of the problems common to aging inner cities, including high crime and physical decay. Since its official designation as an independent city in 1938, city leaders have struggled to alleviate their "big city problems" with "little city resources". The administration is aggressively and successfully working to improve conditions in the community. Under the current administration, the historically high crime rate has dropped by over fifty percent and an ongoing revitalization can be seen throughout the City.

There are approximately 6,000 people in South Tucson, 90% of whom are minorities, and the predominant group is Mexican American. Most residents have low to moderate incomes, many residents have never completed high school, and unemployment is higher than in the greater Tucson area. Over 14% of the residents are 60 years of age and older and over 25% of the 1,810 households have an individual over the age of 65 in residence (U.S. Census Bureau, 2000).

**COPE Behavioral Services, Inc. (COPE)**, a non-profit behavioral healthcare organization, was incorporated in 1974. With more than 30 years experience, COPE provides treatment and rehabilitation services for substance abuse, general mental health, traumatic brain injury, and serious mental illness. COPE offers integrated substance abuse services for adults with physical disabilities and manages a job development program for the homeless. In addition, outreach, education, and early detection services for at-risk populations are provided through COPE's Health Promotions Program. COPE has developed specialized behavioral health services for elders who are difficult to engage.

**The University of Arizona, Center on Aging** was established in 1980 as one of a network of Long Term Care Gerontology Centers originally authorized by Title IV-E of the Older Americans Act and funded by the Administration on Aging. These centers functioned as national resources for the education and training of health and social service personnel, the development and testing of model services, interdisciplinary research and the provision of information and technical assistance on long-term care issues. In 1991, the Center became one of the Board of Regents approved Centers of Excellence within the Arizona Health Sciences Center.

# Need for Culturally Specific Caregiver Programs

# NEED FOR CULTURALLY SPECIFIC CAREGIVER PROGRAMS

There is no all-purpose service that can be provided to an "average caregiver". Each caregiver is unique and culture is a major variable that determines their needs. Culture also defines how and from whom assistance will be accepted. An acknowledgement of this diversity among caregivers is essential in the design of culturally sensitive and appropriate services and service delivery (Tennstedt, 1999).

Before beginning a caregiver support program, it is important to obtain background information from previous programs or research that can provide initial insights to cultural norms, beliefs, values, and behaviors. However, caution must be used when interpreting the information to avoid approaching your project with stereotypical concepts of a culture that may mask the individuality of each caregiver.

For the purposes of Cuidando con Confianza, a review of the literature pertaining to Latino caregivers was compiled and is provided here as an example of the first step in developing a caregiver support program.

## Latino Caregivers

Seventy-two percent of Latino households provide informal care to friends or relatives (Administration on Aging, 2001). Seventy-seven percent of Latino care recipients get help from their spouse or child versus 60% in the general population, yet it is unclear whether this is a product of a cultural preference or the effect of language differences (Aranda and Knight, 1997). Latino caregivers are typically females in their forties, half of whom have children 18 years of age or younger, and they are more likely to be dealing with the complex care of an elder with diabetes. In addition, Latinos have historically held jobs that involved hard labor, leading to higher levels of functional disability beginning near 45 years of age and carrying with it significant implications for the types and duration of care that must be provided.

There are some characteristics and methods of providing care that are relatively common to all Latinos. Gallegos (1991) along with most other authors note a strong, extended family network of informal care and a higher likelihood of multigenerational living arrangements. Caregiving between generations serves as a natural helping network and is often the basis for links to formal systems when younger members are involved (Fried and Mehrotra, 1998). Household members develop strategies to obtain and distribute resources such as time, finances, and the physical and emotional investments that are essential to the task of caregiving. These strategies are shaped by traditions and cultural values and can only be identified by the caregivers themselves.

Hooyman and Kiyak (1999) agree that multigenerational living arrangements are more common among Latinos; however, they claim that this practice is declining. Others who note this decline attribute it to increased urbanization, modernization, mobility, and to the acculturation of the younger members of the community that is challenging the values of familial support for their elders (Gallegos, 1991; Hooyman and Kiyak, 1999).

Traditionally, elderly females expect their children to share their homes and care for them (Fried and Mehrotra, 1998; Holmes and Holmes, 1995); however, Kart (1997) claims that it is no longer safe to assume that a high level of care is being provided by extended families. Increasingly, community elders are becoming dependent on neighbors and friends to supplement their care (Hooyman and Kiyak, 1999). This trend is also indicative of the future need for more social services (Gallegos, 1991).

Latinos rarely institutionalize their elders (Holmes and Holmes, 1995) and the under-utilization of nursing homes is a good indicator of the prevalence of extended family caregiving (Kart, 1997). However, Kart (1997) and Holmes and Holmes (1995) also note an increasing trend toward a nuclear family structure among Latinos. Kart (1997) goes on to speculate that the urbanization of families and the social education of younger family members are causing a decrease in family status for the elderly members of Latino families. These social processes have serious implications for the future delivery of service to the elderly and their family caregivers.

Formal services contradict the cultural norms of responsibility among Latinos. In general, they only seek out formal services when they have become overwhelmed by their caregiving tasks (Fried and Mehrotra, 1998). The choice to turn to formal services often leads to conflict and stress among family caregivers. While mutually supportive, kinship networks are thought to mitigate stress (Sotomayor and Randolph, 1988), the *individual* stress associated with the decision to turn to formal services is often compounded by the existence of multiple family caregivers that must take part in the decision (Aranda and Knight, 1997). Combined with the stress of transition to more formal services is the guilt felt by caregivers who are no longer able to provide the necessary level of care for their family members (Holmes and Holmes, 1995). It is, therefore, imperative that the design of supportive services be conducted with a full awareness of the psychological impact that is occurring during the transition to formal services.

Given that Latinos are facing a lifestyle in the throws of transition, service providers must be acutely aware of this population's traditional sense of filial obligation and the ensuing guilt that results as their role is redefined by the urbanization and modernization of their communities. As noted in the AARP (2001) study of caregivers aged 45-55 years, defined as "the sandwich generation", Latino families emerged as the most family-focused of all groups with caregivers paying a high price for the large role that they take in caregiving to family members. In the AARP study, comparing the characteristics of various racial and ethnic groups, Latinos demonstrated the highest level of helping with the more difficult tasks of personal care yet reported feeling "guilty that they did not do enough". This sense of guilt is a major contributor to the stress that is felt by these caregivers and demanded the inclusion of the expertise from a behavioral health agency to provide assistance with these issues.

Counseling and reassurance to relieve guilt should be available from counselors who are sensitive to the cultural experience, norms, and values of the population (Fried and Mehrotra, 1998). In addition, service providers must take into consideration the fact that

Latinos, particularly Mexican Americans, are less likely to utilize professional mental health services or to even talk about their feelings with regard to the burdens they face as caregivers (Aranda and Knight, 1997).

Services that provide outreach, advocacy, and information about resources should be community-based (Hooyman and Kiyak, 1999). A referral network should utilize community organizations with trained personnel who are culturally compatible with the target population (Connell and Gibson, 1997) and who understand the implications of the changing family structure in their community (Gallegos, 1991). Involving ethnic elders in the design of the program will also make services culturally meaningful and appropriate. Information for distribution must be made available in a language that is meaningful and relevant to specific generational experiences. All forms of intervention must build from the sense of cultural identity that exists in the social support systems and cultural context of their neighborhoods and communities (Hooyman and Kiyak, 1999). Programs must also identify methods and interventions that help to promote and sustain the extended family model of caregiving.

## Summary

A review of the literature pertaining to caregivers, that incorporates cultural views and norms, is the first step in developing a successful program. The above example that was used to identify the cultural aspects of Latino caregiving served as a broad need assessment and provided direction for the project. In addition to identifying the demographic of an average Latino caregiver, the review identified important information such as living arrangements, kinship networks and filial obligation. At the same time, it identified the impact of acculturation, modernization and mobility on the family structure and how these issues leave the current generation of caregivers caught between their traditional values and their economic needs. Two equally important issues, raised in this review are the importance of involving ethnic elders in the design of the program and that the program needs to be community based.

# Accessing the Community

# ACCESSING THE COMMUNITY

Several critical factors are involved in the delivery of responsive and acceptable services to ethnic populations. Central among these factors is the pervasive role of culture in mediating the intergenerational caregiving activities of family members and households. Decisions about whom caregivers and family members will trust, methods used to learn about services and healthcare systems, and decisions regarding the acceptability of services are all mediated by cultural beliefs, values, and practices.

Often considered outsiders, formal service providers have had problems in earning the trust of those individuals who may be in need of assistance. According to Fried and Mehrotra (1997), in communities that are highly defined by the predominant culture, outside formal service providers cannot assist these caregivers until acceptance of the services has been established in the community. Yet, in geographic areas that have high concentrations of one minority population, it is particularly difficult to gain access and acceptance by the community. The residents are often studied and researched to the point of feeling like they are living in a fish bowl, thus increasing the mistrust of outsiders. To ensure the acceptance of supportive caregiver programs, access to the caregivers has to occur through trusted community members. It was important to inform the community that project staff was not there to conduct research or observe their behavior. The project was identified as a method for caregivers to make their particular needs known to the service providers, and then to establish long-range, sustainable services in the community.

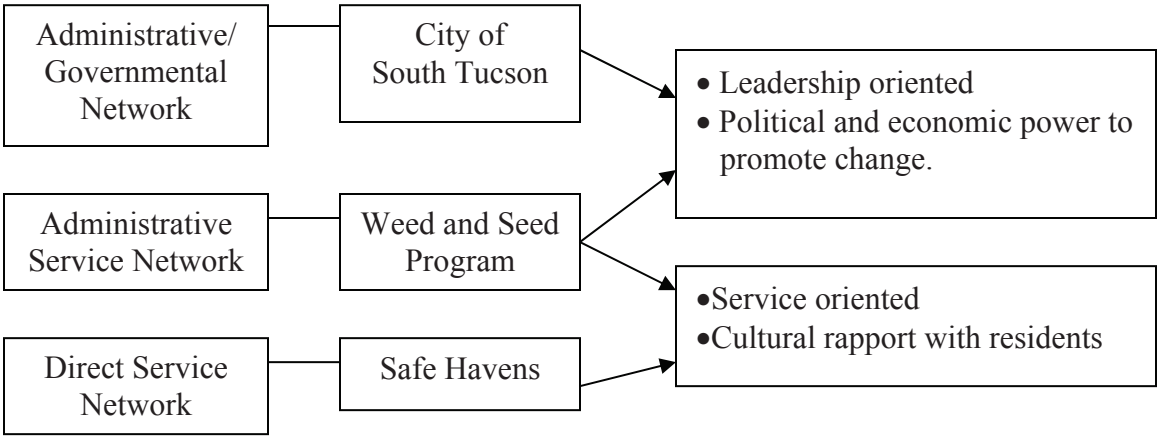
In general, there are two methods of accessing culturally defined communities. The first is through the network of administrative and governmental agencies that have the influence and power to facilitate change. A second avenue of access is the network of direct service providers who are in daily contact with community members and who have developed the trust of the community. Cuidando con Confianza utilized both networks to gain access and acceptance in the City of South Tucson.

In South Tucson, the administrative and direct service networks are linked through a Weed and Seed Program. Weed and Seed programs are federal grant programs from the U.S. Department of Justice, intended to revitalize low-income and high crime areas of the country. The funding provides for enhanced law enforcement and community policing to work more closely with the residents. Law enforcement receives better equipment and is able to spend more time in the field. And the officers receive specialized training in problem solving, community relations, cultural sensitivity and conflict resolution. They are out there with the residents and given the success of the program in South Tucson, have earned the respect and trust of the residents.

Through this funding, neighborhood restoration includes citywide clean ups and opportunities for the business community to work with neighborhood residents, social agencies, schools and city staff to eliminate blight and slums. So these programs really do weed out what is undesirable in a community and then plant the seeds for new growth.

The further prevention of criminal activity is obtained through the development of youth oriented programs that are based at locations known as Safe Havens.

Safe Havens are the cornerstone of the prevention portion of Weed and Seed Programs. They are multi-service centers, mainly targeting youth, but they also serve as the conduit for many service agencies that exist in the community. They are known as "the place to go" and the staff members are trusted members of the community. Safe Havens were the service delivery network used in Cuidando con Confianza.




In most culturally defined communities, there are similar structures at work. Certain members or agencies within the community serve as culture brokers and provide the route of access to the residents. These community members have earned the trust of the residents and can exist at one or all levels of the community structure. For Cuidando con Confianza, the City of South Tucson had the capacity to bring in resources and develop community ties. The Weed and Seed Program was working with both the City and the residents to revitalize the community. And the Safe Havens were the direct point of contact with the residents.

Accessing these political and service networks provided Cuidando con Confianza with a trusted community structure, capable of performing the initial outreach and engagement tasks of the program. Secondary outreach and engagement was conducted through faith-based organizations, primary health care facilities, and civic groups.

**Summary**

Access to a culturally defined community can only be gained through trusted community members and agencies. Those with the influence to affect change and those who provide direct services are the community culture brokers who provide the linkage between outside service programs and the caregivers in need of services. Accessing these systems is the first step in developing successful caregiver support programs.

# Defining Caregiver Needs

# DEFINING CAREGIVER NEEDS

A primary component of Cuidando con Confianza was not only to recognize the model of caregiving that exists in Latino communities, but to implement programs that address the specific, *perceived needs* of the South Tucson, Mexican American target population. To accomplish this task, Cuidando con Confianza implemented an empowerment model that recognized the need to redefine service "recipients" as project "resources". In South Tucson, family caregivers were the "resource" targeted for the design and development of the program.

Project partner and caregiver focus groups were utilized to develop strategies to respond to the community's perception of the problem in a manner that was culturally and linguistically sound. The role of PCOA and COPE was to provide infrastructure to assist the process. The role of the University Center on Aging was to provide ongoing oversight and evaluation of the project. All participants provided information, resources, and support to community meetings and activities identified as necessary to establish a community-based caregiver support program. This project went beyond the traditional methods of trying to determine what caregivers need. Rather, the project provided a method to assist South Tucson caregivers in making that decision for themselves.

## Community Level Focus Groups

The first six (6) focus groups were conducted with a mix of city personnel and caregivers to define the overall community need and solicit recommendations for the development of the implementation plan. These members identified two critical elements to the success of the program. The first was that all activities must be community based and provided by service providers that were known to and trusted by the residents. The second was that the project must fit with the cultural norms of the community.

To address the first element of community based services, the project was established at three of the community Safe Havens. Safe Haven staff provided transportation to the sites, meeting rooms, refreshments, and local leadership for the project. Their initial buy-in to the project and subsequent support, established these sites as sustainable points of contact for South Tucson residents to acquire information, referral and services for elders and caregivers.

To design a project that would fit with the cultural norms of the community, city leaders and residents advised that the project should incorporate the key social values of the community, which are "Family, Faith, Food and Fun!" Each of these values was examined to develop the project format. The success of the project was dependent on the incorporation of these community values and norms.

**Family** was an important component. Most of the caregivers were middle-aged daughters, caring for a parent. The parent lived in the caregiver's home, along with the children and sometimes grandchildren of the caregiver. Meeting times needed to be established during the evening to allow for the teenaged children to be home from school

to care for the elder and younger children, while the caregiver participated in the project activities. The caregivers in the group also noted the tremendous demands on their time and asked that project activities be scheduled every other week, in the evening, instead of once a week. So an important initial finding of this project was that caregivers in multi-generational households consider the needs and schedules of their family members when attempting to establish a timeframe to participate in support activities for themselves.

The incorporation of the **faith** of the caregivers was not a structured component, from the start, but a natural transition during the course of the project. The majority of residents in South Tucson are Roman Catholics. As the caregivers met and began to know one another and felt comfortable with one another, they would often take time to pray for each other and for their care recipients. During the second year of the project, the participating caregivers established an actual prayer group on another night of the week and invited project staff to attend. When a caregiver faced the loss of their elder, the group and staff would attend the religious services. The caregivers also noted that conducting outreach through faith-based organizations would have benefited the project so presentations about the project were made during Lenten services, in Year One, at local churches.

The elements of **food and fun** were just as important as the first two project dimensions. The Safe Havens provided refreshments at each workshop and support group meetings, through project funding. In addition, a year-end celebration of "caregivers" was provided by the lead agency. This was a sit-down dinner in a local restaurant, complete with Mariachi music, where the caregivers danced and sang and shared their stories.

## Caregiver Level Focus Groups

After soliciting community level input, fifteen (15) focus groups comprised of community caregivers were conducted during the next two months of the project. Having the community level overview of the specific needs with respect to access issues and the cultural values and norms of the community, these groups were convened to address the specific needs of the caregivers. Topics of discussion were:

- Exploring their attitudes about caregiving
- Defining the outcomes of their caregiving experience
- Defining the best methods for conveying project information, conducting outreach, and engaging caregivers
- Defining the types of activities that would provide the most caregiver support
- Defining the types of ancillary services that would assist the caregiver

Table 1 summarizes the issues and responses of the caregivers.

**Table 1 – Summary of caregiver focus groups**

| TOPIC | ISSUES/RESPONSE |
|---|---|
| **Attitudes about caregiving** | • Caregiving is a family obligation<br>• Depression is prevalent among both the caregivers and elders<br>• Elders are reticent to accepting assistance from anyone other than family |
| **Caregiving experience** | • Difficulty navigating the healthcare system; need translators<br>• Experience with nursing homes resulted in substandard care and guilt for caregiver<br>• Low income affects how care can be provided<br>• Caregiving is causing family conflict<br>• Most all caregivers are multi-tasking between parents, children, jobs and are highly stressed |
| **Outreach and Engagement** | • Outreach should be conducted door-to-door to find caregivers and offer assistance<br>• Retention in program is depended on time constraints of the caregiver and transportation |
| **Activities for program** | • Workshops related to health issues<br>• Workshops related to formal service systems<br>• Support groups with an open topic format<br>• Parties |
| **Needed services** | • Transportation<br>• Activity for the elders<br>• Respite care |

## Summary

A significant finding, from these focus groups was that the typical type of structured caregiver support program wouldn't work for this culturally defined area. As an example, project staff proposed a structured, and commonly used, type of educational meeting format in which the caregivers would meet weekly to discuss preset topics such as nutrition, conflict management, etc. followed by a series of support groups with preset topics such as grief, physical caregiving, etc. These did not fit with the schedule or needs of the South Tucson caregivers. As mentioned, their time was limited and their needs were different. Their main concerns were for health education, access to resources, and some time to talk and relax.

# Implementation Plan

# IMPLEMENTATION PLAN

Although our objective was to develop a "community defined" program, we also needed some type of organizational structure to define our role, activities and responsibilities to this project. Below, we have included our action plan, timeline and strategies as a model to assist other programs with this aspect of program development.

## Plan of Action

Cuidando con Confianza was implemented in the following three phases:

Phase I included all of the pre-program activities that were needed to establish the resources that are necessary for a successful project. In general, they include strategies that recognize the importance of utilizing trusted community residents and include:

- hiring of key personnel
- establishment of cooperative agreements with project partners
- training of key and ancillary personnel
- establishment of community focus groups
- community identification of issues to be addressed
- community identification of program design
- community development of informational materials

Phase II was to implement the initial outreach programs in a manner that had been determined to be culturally appropriate and acceptable for this community and that recognized the need to provide services via trusted community members:

- Implementation of community outreach to develop community awareness of the project
- Establishment of community-based points of contact for activities
- Further dissemination of information through primary and secondary organizations
- Recruitment of family caregivers to project activities

Phase III was to implement specific programs and activities for family caregivers:

- Provision of educational workshops
- Provision of varied caregiver referral services
- Establishment and facilitation of caregiver support groups

## Timeline

A chronological table of the plan of action specifying the action to be taken and the target dates is provided as Table 2.

**Table 2 – Timeline of Phase Level Actions and Target Dates**

| Phase | Activity | Target Date |
|---|---|---|
| I | Hire project director;<br>Hire bilingual/bicultural behavioral health specialist. | Days 1 – 30 |
| I | Establish cooperative agreements with project partners | Days 1 - 30 |
| I | Train key and ancillary personnel. | Days 30 – 45 |
| I | Establish community focus groups. | Days 30 – 45 |
| I | Identify issues to be addressed. | Days 45 - 60 |
| I | Identify program design. | Days 45 – 60 |
| I | Develop informational materials. | Days 60 – 90 |
| II | Implement outreach programs. | Days 90 – Ongoing |
| II | Establish community based points of contact. | Days 90 – 120 |
| II | Implement additional outreach via second line organizations. | Days 120 - Ongoing |
| II | Recruit caregivers to programs. | Days 90 – Ongoing |
| III | Provide educational workshops. | Days 120 – Ongoing |
| III | Provide referral services. | Days 120 – Ongoing |
| III | Establish and facilitate support groups. | Days 120 - Ongoing |
| From Day 1 | Collect data. | Days 1 – Ongoing |
| From Day 1 | Monitor, evaluate, and adapt project as needed. | Days 1 – Ongoing |

**Implementation Strategies by Year**

Year one activities were: to develop the focus groups that determined the project model and materials; to establish and activate the community outreach program; and to provide caregiver support programs that included referral to formal services, educational workshops, and peer support groups. The expected outcomes of the year one activities were the identification of the caregiver practices and needs specific to the culture, the development of a culturally acceptable model of supportive services for family caregivers, and the initial acceptance of interventions that reduce caregiver stress.

During years two and three, the project emphasis was to maintain and expand the year one activities, to monitor and adapt project programs as defined by community stakeholders, and to provide professional assistance to ensure the sustainability of the project.

**Training**

It was necessary to train the fire, police, and Safe Haven personnel in order to establish this community-based project. These individuals participated in workshops on aging and behavioral health issues that are pertinent to caregiving as defined in the professional literature in these areas. Additional training was focused on the availability of formal service providers and methods of contact. Specialists in the fields of aging and

behavioral health conducted these training sessions. After the development of the program model, the specialists provided training on the implementation of the program components.

## Method of Evaluation

A qualified research specialist from COPE worked with researchers from the University of Arizona Center on Aging to conduct a rigorous evaluation of the project. The evaluation was a continuous process beginning in month one and ongoing for the duration of the project. The goal-oriented evaluation methodology incorporated structure, process, and outcome measures to emphasize the relationship between activities and outcomes and the desired results and objectives. The project evaluation consisted of three major components: 1) project implementation report; 2) objectives and activities outcome summary; and 3) caregiver outcomes related to the community-based intervention model.

The evaluation methodology used as its framework, The Family Caregiving Dynamics Model based on McCall and Simmons' (1976) paradigm of symbolic interactionism. Program evaluation activities used this framework to examine the perceptions, structure, and the interaction and situational context of caregiving and how these relate to personal, affective (positive and negative), and behavioral outcomes of caregivers. Variables assessed included: expressions/feelings attributable to caregiver-elder relationships, the caregivers' overall impression of the elderly person derived from multiple comparisons of past and present images, ethnicity, type of relationship, history of relationship and family solidarity. Information was obtained related to the elder's ADL abilities, cognitive capacity, situational stress, affective state and social support (formal and informal assistance). Caregiver outcome measures included caregiver burden and guilt and change in social support network, affective state, and behavior (improved caregiving skills and techniques and interaction between elders and caregivers).

## Summary

The action plan, timetables, and strategies used on this program provided administrative structure while also maintaining flexibility as the program developed. An important component of the plan was the continual evaluation of the program, its progress and outcomes. A second component was the need to train local staff and project partners in the areas of aging and behavioral health. As many civil servants and social service providers were to be involved in the project, it was imperative that they have background information on the issues of aging, caregiving, and appropriate community resources.

# Program Activities

# PROGRAM ACTIVITIES

The Cuidando con Confianza activities were defined by the caregivers and implemented by the project partners. Workshops and groups were held on a rotational basis at three Safe Havens in the community. Below, we have included a summary of our workshops, support groups, and ancillary activities as a model to assist other programs with this aspect of program development.

**Educational workshops related to health education**

How to check pulse, temperature and respiration with older adults
Diabetes
Alzheimer's and related dementias
Caregivers and exercise
Issues in aging
Mental health of older adults
Mental health of caregivers
Nutrition
Cancer
Blood pressure and cholesterol

**Educational workshops related to community resources**

Medicare and Health Maintenance Organizations
Community Services System
Respite care
Neighborhood Alliance and Ambassador Programs
Home repair programs
Emergency alert systems
Fire prevention and home safety

**Support group topics**

Taking care of yourself as a caregiver
Services that are needed in the home to provide care
Holiday pick me ups
The importance of prayer in a caregiver's life
Feelings about the use of nursing homes
The care recipient
Family dynamics in caregiving
Death and an afterlife
Guilt
Isolation in caregiving
Need for support
One whole evening of jokes and laughter!

**Ancillary activities**

Holiday parties
Community surveys of caregiver needs
Provided home health and safety equipment
Provided personal care items for caregivers
Home visits to caregivers
Attendance at funerals
Annual celebration of caregiving/caregivers!

**Summary**

Attendance and retention in the program activities was consistent throughout the three years of the project. The caregivers developed mutual bonds that extended to helping one another with caregiving needs, forming a prayer group outside of the program, and supporting each other during the loss of their care recipients. Caregivers who lost their elder during the course of the program continued to attend the workshops and groups to lend support to others. We were unable to assess whether this was a product of culture or an outcome of consumer directed program development, but were pleased, nonetheless.

# The Caregivers

# THE CAREGIVERS

**Profile of the Caregiver Participant**

The following is a brief description of the characteristics that define caregivers who participated in the program:

- All caregivers were female with an average age of 59.75. About three-quarters were married and had an average of eight years of formal education.
- Most often caregivers were either the female spouse or daughter of the elderly relative receiving care.
- Caregivers most often helped the elder with homemaking, coordination of financial matters, socialization, transportation and management of legal matters. The average age of the care recipient was 75.17 years.
- Caregivers provided an average of 9.6 hours of care per day for elderly relatives
- All but one caregiver had provided care for five years or more
- Almost all the caregivers were unemployed and about 40% indicated that caregiver responsibilities kept them from seeking employment.
- Three-quarters of the caregivers indicated being totally satisfied with their caregiving experience and believe they are doing the best they can for their elderly relative. About 40% reported feeling hardly any stress from their experience as a caregiver.
- Almost 40% of the caregivers are also responsible for the care of other family members.
- About one-half of the caregiver households were two person households while two households had 11 permanent residents. About one-half were one generation households.
- About 66% of caregiver households had an annual income of $20,000 or less. About three-quarters of these had household incomes of $10,000 or less.
- The majority of caregivers had current health problems.
- As a result of their caregiving experience, caregivers were most likely to see changes in their weight, the amount they worried about things and their stress levels. Almost all indicated that a change in their weight was a good change. Also those caregivers who excessively worry and have high stress/tension levels experienced a positive decrease in both these traits since participating in the program.

- Three-quarters of the caregivers were raised solely in Mexico while three were raised only in the United States.

- Caregivers' participation in religious activities was only moderately affected by their caregiving responsibilities. However, about one-half visited with friends and family as well as took part in group activities less often. Only 33% reported not having enough time to themselves and experiencing a decrease in their social activities.

- The majority of caregivers indicated feeling pressured to meet responsibilities to the elder care recipient and other family members.

- Overall, the caregivers were receiving very few formal community support services. The majority reported that services they received helped them to be a better caregiver. Also, the services they received enabled them to provide care for their elder for a longer time than would have been possible without these services.

- About one-half of caregivers received some respite from their caregiving responsibilities from other family members, friends and/or volunteers. On the average, caregivers received respite assistance about three times a week for four hours at a time. Of those caregivers receiving time off from their caregiving responsibilities, only one said they could use more hours of respite per week.

## Caregiver Assessment of the Program

During the final year of the project, a short survey was conducted, with the caregivers, to summarize how they felt about the project. Below are some of the questions and excerpts from those surveys.

1. Why did you decide to participate in this program?

To help take care of people.
To receive more help for my mother and learn to take care of her in her old age.
Because it helps us a lot.
I was invited and enjoyed getting together with others going through the same thing.
To help myself as a caregiver.

2. What services did you receive from this program that you did not receive before?

Health care information.
Comradery.
Fire alarms. Support. Very important information.
A chair for the bathroom.
Information.

3. If this program did not exist, where would you have looked for services?

I wouldn't know where to look for services.
Probably through my mother's senior citizen group.

4. What is the most important thing you have learned from this program?
Information about illnesses and how to help ourselves.
What to do when a sick person dies, Medicare services, information about diabetes.
I am not alone taking care of an elderly.
To get along with a lot of new people.
There are a lot of people out there that take care of others. There are others that are willing to share their support.

5. By participating in this program, do you feel better as a caregiver?
Yes, I feel very confident because of the things I have learned.
I learned how to take care of people.
I learned a lot.
Much better. And more knowledgeable about resources that are available.
Yes.

6. Which group or workshop do you remember the most?
Diabetes.
Diabetes and information on Medicare.
The times we got together just to socialize and vent.

7. Do you think the locations were appropriate?
It was nice rotating between new scenes every month and they were all convenient to get to.
Of course, it is very close to my house. I actually walked there.

Additional questions on the effectiveness of the facilitator and the choice of topics received similar positive responses. Overall, the caregivers felt that they had benefited from the program from both the educational and social aspect of the groups.

**Community Impact**

The caregiver responses, workshops, groups and events are the project accomplishments that can be quantified. But the existence of the project also resulted in many qualitative changes in the community. Before this project, the focus of the Save Havens was to provide services and activities targeted to the youth in the community. Cuidando con Confianza brought a new focus on the needs of the elders and caregivers, in the community, to these sites. Site staff are now able to provide information for elders and caregivers and able to refer them for appropriate services. An increased awareness of the needs of elders and caregivers also developed among the city personnel who were involved in the project. City fire and police personnel are now prepared to refer elders in need to the Safe Haven locations, during the course of their routine calls. Group activities will be sustained at the Safe Haven sites, and additional funding has been sought to expand services to the elderly and caregivers in South Tucson.

## Summary

It is evident that a caregiver support program was needed in the City of South Tucson. By utilizing a community empowerment model, Cuidando con Confianza not only provided that support, but caused a positive change in the community and its services to elders and caregivers. The program provided caregivers access to a previously unavailable resource that offered emotional support and guidance that heightened their competence and capabilities as caregivers.

# Observations and Recommendations for Service Providers

## OBSERVATIONS AND RECOMMENDATIONS FOR SERVICES PROVIDERS

This guide has provided the methodologies for developing culturally acceptable caregiver support programs and included our outcomes. Over the course of the three year project, staff have also documented observations and insights gained while working with these remarkable caregivers. These outcomes of the project are also valuable information for other service providers who plan to establish caregiver support programs.

Health literacy is low among this population, yet the caregivers recognized the need to not only know how to address the health of the elder, but to maintain their own health in order to provide care. Diabetes is a common disease among Mexican Americans and was one of the first topics that they requested for a workshop. As the project progressed, several workshops were conducted to address health and nutrition and the caregivers incorporated this new knowledge into their daily lives. As a small example, the group snacks even changed from cakes, pies and doughnuts, to fruit, cheeses and grains over the course of the project, and at the caregivers' request.

The front line staff must be bilingual and bicultural in order to understand the many nuances of the culture. Facilitators must also be able to bridge and eliminate socioeconomic barriers that exist due to strong class systems among Mexican Americans. The facilitator should be as close to the socioeconomic level of the group as possible to avoid being viewed as an authoritarian figure that may be respected, but not trusted. The facilitator must also work to put the control of the group into the hands of the caregivers. In this project, the caregivers defined all workshop and support group topics and project staff was utilized to coordinate the activities (scheduling, acquiring speakers, etc.), but not lead them.

Another finding of this project was that service providers must consider literacy levels in various aspects of their projects. During the survey process, it was identified that the surveys must be obtained through verbal questioning to control for limited literacy. This also limited the amount of printed materials that were developed by the project. Although small, bilingual brochures about the project were distributed at sites throughout the community, most participants engaged through word of mouth or by invitation from city and Safe Haven personnel. Media interviews were also utilized to inform the community about the project.

And a final finding of this project was that many of the myths about Mexican American caregiver preferences do not hold up in the field. For example, there is literature stating that Mexican Americans do not access formal services due to cultural and familial norms that dictate family taking care of their own. In reality, the caregivers identified that the lack of formal service use was due to a lack of access to services, particularly in the area of health care. Transportation to services was an issue, as was the ability to pay for services or qualify for subsidized care. Service agencies that do not employ bilingual staff also presented an obstacle for the caregivers. Overall, the caregivers agreed that low

income was the primary obstacle in obtaining services. They also noted reluctance among the elders to accept care from anyone but family members. However, this did not diminish their need for formal services.

And finally, while the majority of support group discussions were about caregiving, family dynamics and problem issues, sometimes the caregivers just sat and told jokes all evening, to relieve their stress and forget about their caregiving and family issues. This need for "time to just relax away from it all" is a finding that should be incorporated in all caregiver support programs.

# Resources Developed on the Project

## RESOURCES DEVELOPED ON THE PROJECT

During the first year of the project, a small brochure was developed to be distributed throughout the community, along with a survey to assess the community's caregiver needs. For use by staff and at the local service sites, a local information and referral notebook was developed by PCOA. This notebook contained information on community resources, congregate meals and mobile meals, the Community Services System, Home Care Agencies, and a housing directory. It also noted which service providers in the greater Tucson area had bilingual staff. A limited number of hard copies are still available through PCOA.

A Caregiver Survey was developed to obtain demographic as well as physical and emotional health, behavioral, psychological and service utilization data for both the elder receiving care and the caregiver. The survey was developed using instruments that have been tested among Hispanic populations and found to be valid and reliable measurements. The survey consent form as well as an outline of the major components of the survey are included as an appendix to this guide.

# References

# REFERENCES


AARP (2001). In the middle: a report on multicultural boomers coping with family and aging issues. Washington, D.C.

Aranda, M.P., and Knight, B.G., (1997). The influence of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. The Gerontologist, 37 (3), 342-354.

Connell, C.M. and Gibson, G.D., (1997). Racial, ethnic, and cultural differences in dementia caregivers: review and analysis. The Gerontologist 37 (3), 355-363.

Fried, S.B. and Mehrotra, C.M. (1998). Aging and diversity: an active learning experience. Washington D.C.: Taylor and Francis.

Gallegos, Joseph S., (1991). Culturally relevant services for Hispanic elderly. In Sotomayor, M. (Ed), Empowering Hispanic families: a critical issue for the '90s. Milwaukee: Family Service America.

Holmes, E.R. and Holmes, L.D., (1995). Other cultures, elder years, 2nd ed. Thousand Oaks: Sage.

Hooyman, N.R. and Kiyak, H.A., (1999). Social gerontology: a multidisciplinary perspective, 5th ed. Boston: Allyn and Bacon.

Janevic, M.R. and Connell, C.M., (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. The Gerontologist, 41(3), 334-347.

Kart, C.S., (1997). The realities of aging: an introduction to gerontology, 5th ed. Boston: Allyn and Bacon.

McCallo, G. and Simmons, J. (1976) Identities and interactions. New York: Free Press.

Sotomayor, M. and Randolph, S., (1988) A preliminary review of caregiving issues and the Hispanic family. In Sotomayor, M. and Curiel, H. (Eds). Hispanic elderly: a cultural signature. Edinburg, TX: Pan American University Press.

Tennstedt, S., (1999). Family caregiving in an aging society. Presented at U.S. Administration on Aging Symposium: Longevity in the New American Century, March 29, 1999. Baltimore.

U.S. Administration on Aging, (2001) The many faces of aging. Washington, D.C.

# Appendix A: Caregiver Survey Content Outline & Consent Form

# APPENDIX A:

# CAREGIVER SURVEY CONTENT OUTLINE & CONSENT FORM

## CAREGIVER SURVEY CONTENT OUTLINE

The Caregiver Survey was designed specifically for use by program participants from South Tucson, Arizona keeping in mind two important considerations: 1) the highly defined and predominate Hispanic culture, and 2) literacy levels of the older adult population living in the community. Both English and Spanish versions of the survey are available.

The survey was divided into the following sections: *1) Participant Consent Form (see attached); 2) Initial Caregiver Assessment; 3) Caregiver Demographics, and 4) Ethnicity and Family Background, Caregiver Burden and Services Assessment.* The survey was structured to be administered in three parts. The Participant Consent Form and Initial Caregiver Assessment were administered by a trained field researcher as an in-person interview. The Caregiver Demographics portion of the survey was designed as a self-report questionnaire. The final section (Ethnicity and Family Background, Caregiver Burden and Services Assessment) was administered in-person by the field researcher. Also, this follow-up meeting allowed the interviewer and respondent to complete any of the self-report questions that were not clear and/or those respondents did not understand.

The following is a description of each component of the Caregiver Survey:

**Participant Consent Form** (attached)**:** The form was structured using a question and answer format to promote understanding and clarity. The purpose and benefits of the survey as well as participants rights were described. A verbal explanation of the consent form was provided if the interviewer sensed that a participant did not understand the written form.

**Initial Caregiver Assessment:** Questions in this section of the survey were designed to obtain participant information in the following areas:

- the caregiver's relationship to the elder receiving care
- living arrangements
- services (personal care, homemaking, transportation, coordination of relative's care, coordination of financial matters, management of legal matters, and socialization) provided by the caregiver and hours per day spent providing each service
- identification of the primary caregiver
- the length of time the caregiver had been providing care for their elderly relative
- identification of persons, other than the caregiver, that helped with each of the above services: relationship to caregiver; paid or not paid; age, and caregiving hours spent each week

- ☼ total hours of care required by the care recipient provided by all caregivers
- ☼ employment status of the caregiver; if the caregiver left a job or educational pursuit in order to provide care to an elderly relative; and if caregiving responsibilities kept the caregiver from seeking employment
- ☼ Caregivers were asked to rate (from 1= best to 5= worst) their caregiving experience on three dimensions: satisfaction, performance and stress
- ☼ Caregiving responsibilities for other relatives, including: relationship to caregiver; age; living arrangements; disability status, and hours spent providing care for other relatives

**Caregiver Demographics:** This section of the survey was structured as a self-report questionnaire. The interviewer was instructed to leave this portion of the questionnaire with the caregiver at the completion of the in-person initial assessment. Questions in this section of the survey were designed to obtain caregiver information in the following areas:

- ☼ Caregiver characteristics: gender; age; marital status; years of formal education completed; primary occupation (in terms of overall life span); annual household income
- ☼ Age, gender and marital status for permanent residents of households where the care recipient and caregiver live in the same household
- ☼ Age, gender and marital status for permanent residents of caregiver households where the care recipient does not live with the caregiver
- ☼ Total number of permanent residents and generations of family members residing in the household
- ☼ Identification of home ownership
- ☼ Health and functional status of the elderly care recipient: a) The caregiver was asked to identify current health problems and rate how much each health problem stood in the way of what the elder liked to do (from a list of 25 health problems; b) The caregiver was asked to identify those functional and instrumental ADLs the care recipient needed help with by using a four point scale to rate the level of help needed (needs no help; needs some help; needs a lot of help; cannot do at all).
- ☼ Ratings of caregivers and elders overall health status
- ☼ Open-ended reporting of the caregiver's three major health problems, if any.
- ☼ Caregiver's completion of the following scales:
    - *Changes in Caregivers Health Scale (Phillips, L., 1987)* was used to measure any changes that had occurred in caregivers' health status during the past year. This 16 item scale measures the extent of the change (no change, some change, moderate change, great change) as well as the type of change (good or bad).
    - *Familism Scale(Sabogal, Marin, Otero-Sabogal and Perez-Stable, 1987)* was used to measure familism. The scale contains 14 items that measure the degree to which individuals hold strong beliefs regarding extended and nuclear family loyalty, solidarity and reciprocity.

**Ethnicity and Family Background, Caregiver Burden and Service Assessment:** The final section of the survey was administered as an in-person interview with caregivers. In addition, interviewers were instructed to determine if the self-administered section of the

survey was completed by caregivers and, if not, to offer their help to clarify any questions that may have been difficult to understand. Questions in this final section of the survey were designed to obtain caregiver information in the following areas:

- Ethnicity and family background: geographical location of birth; country(s) were the caregiver was raised; language spoken at home; and father and mother's country of birth.
- Care recipient demographics: age; gender; marital status; years of formal education; primary occupation (in terms of overall life span)
- Administration of the *Caregiver Burden Scale (Poulshock & Deimling, 1984)*. Although the scale is designed to be a self-report measurement, the interviewer was instructed to provide caregivers verbal instructions on how to complete the scale. This 26 item instrument indexes cognitive incapacity and ADL burden (burden antecedents), social function burden and disruptive behavior burden (caregiver's perceptions), and social restriction and elder/caregiver/family relationship change (burden outcomes).
- Assessment of current service utilization, past utilization and service need. A list of 22 community agencies and organizations was developed by evaluation and program staff. Caregivers were asked to identify if they, or the elder, or both were currently receiving any of these services and to rate how satisfied they were with the services they were receiving. This same process was repeated for services that the caregiver or elder may have received in the past but were no longer receiving. Also, this method was used to determine which services that caregivers and elders were currently not receiving and need.
- Caregiver's were asked if other family members, friends or volunteers provided them respite from their caregiving responsibilities. If yes, caregivers indicated: how many times per week for how many hours; whether or not it was enough time off from their caregiver responsibilities and, if not, how many more hours of respite per week were needed.

## CITY OF SOUTH TUCSON

## CAREGIVER SUPPORT PROGRAM:
## CUIDANDO CON CONFIANZA-CARING WITH CONFIDENCE

### Caregiver Survey Consent Form

I am being asked to read the following material to ensure that I clearly understand the purpose of this survey, which is to benefit the Caregiver Support Program, and how I can participate. Signing this form will indicate that I have been so informed of the above and have decided to participate or not participate in a free and informed manner.

**WHY WAS I SELECTED TO PARTICIPATE?** Caregivers of older adults age 60+ living in the City of South Tucson now have the opportunity to enroll in a three year program funded by the Administration on Aging, U.S. Department of Health and Human Services. The purpose of this three year project is to offer assistance to those individuals and families providing care for an adult age 60 years and older. The elder does not have to live in the same home as the caregiver, but should reside in the City of South Tucson.

**WHAT COMMUNITY AGENCIES ARE PARTICIPATING?** Participating agencies in this project include Pima Council on Aging, the City of South Tucson, COPE Behavioral Services, and the University of Arizona Center on Aging.

**HOW WILL THE INFORMATION OBTAINED FROM THE INTERVIEWS AND SURVEYS BE USED?** The information will be used in helping to develop an effective support program for you the caregiver. It will also be used for reporting the status of the project to the funding source.

**WHAT QUESTIONS WILL BE ASKED?** You will be asked questions that relate to your role as a caregiver, including: amount of time spent on caregiving tasks, general health, social and behavioral information about you and your older relative and service utilization and need.

**WILL INFORMATION BE HELD CONFIDENTIAL?** Yes. All the information will be used for project purposes only. Access to your information is restricted to authorized personnel only. Your name and your relatives' names will NOT be used. You will be assigned a number to be used for identification purposes only.

**WHO IS CONDUCTING THE INTERVIEW?** The interview will be administered by bilingual staff of the Caregiver Support Program and the Arizona Center on Aging, University of Arizona.

**WHAT RIGHTS DO I HAVE AS A PARTICIPANT OF THIS INTERVIEW?** Your participation is important in reporting the status of the project to the funding sponsor and in aiding the continuation of the project. However, your participation is voluntary, you may ask any questions you may have, and you are free to withdraw from the interview at any time without causing bad feelings or affect your participation in the Caregiver Support Program.

**WHAT DO I DO TO PARTICIPATE?** All you need to do is to sign this consent form. Project staff will contact you to schedule a time and place for the interview.

If you have any further questions please feel free to ask the person who gave you this form or the interviewer. If you do decide to participate, please sign below and check the appropriate box. Your signature on this consent form shows that you are aware of your rights as a participant in this interview and understand what you are agreeing to.

I have read the above Statement of Consent. The purpose of this interview has been explained to me and my questions have been answered.

I understand that:

1. My participation is voluntary.
2. I may ask questions.
3. I may withdraw at any time without causing bad feelings.

I understand that this consent form will be filed at the Cuidando con Confianza Program office, with access restricted to authorized Caregiver Support Program staff.

I am choosing to participate ☐

I am choosing ***NOT*** to participate ☐

_____ _____

Participant Signature Date

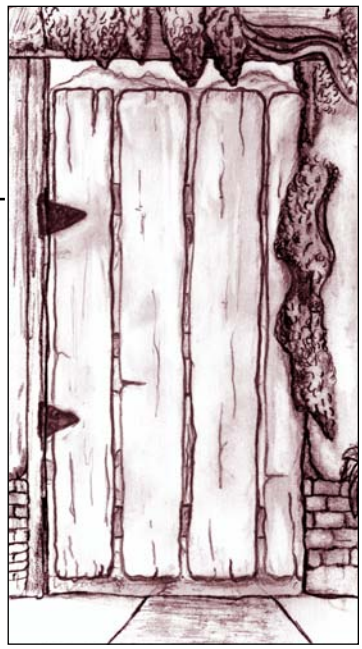
_____ _____

Witness Date

# Appendix B:
# PATHFINDER
# A Guide for Family Caregiving

# ADVANCE DIRECTIVES

*helping older relatives or friends make more informed choices about medical care and/or financial decisions*



## FREQUENTLY ASKED QUESTIONS

As a caregiver, I can see the changes in my loved one that indicate it maybe time for help with medical and financial decisions, but I am not sure where to begin.

### ❖ Where and how does the caregiver start when concerned about the person's ability to adequately handle their finances and medical decisions?

Begin with the understanding that all persons are competent and have the right to refuse treatment or assistance. Open a discussion with the person to determine if they are **willing** to accept assistance from you. If not willing, ask the person if documents have been prepared that designate someone who has agreed to assist them with medical and financial decisions.

### ❖ What if they have not prepared any documents, do not remember, or can no longer communicate?

Obtain permission from the person to contact family members, friends, physicians, and their personal attorney to verify if anyone can confirm the existence of these documents.

### ❖ As the caregiver, do I need some formal documents to be able to make decisions (both financial and medical) or can I just take charge?

**You cannot just take charge without the person's permission.** If the person is willing and accepts your help, a caregiver can assist in a number of ways…..but only up to a point. Depending on the type of assistance required the appropriate legal authority might be needed to make decisions. Also, there may be regulatory issues that might make it difficult to accomplish many tasks without the appropriate documents. **The caregiver (other than a spouse) is not obligated to assume this responsibility. It is important the caregiver understand the nature and consequences associated with undertaking this responsibility.**

### ❖ Why do we need any of these documents?

At any age, one can have an emergency that might temporarily or permanently limit their ability to verbally communicate or **indicate** their treatment choices. Also, each of us has varied cultural, personal and religious beliefs that might influence our decisions. It is important to communicate our beliefs to someone who knows us well and will speak on our behalf if we are no longer able to make medical, financial and other important decisions. It is very important that this person will advocate our beliefs even if their beliefs are different. Documents that provide an opportunity to state how and what type of treatment a person wants prior to the need for those decisions are known as "Advance Directives." **Every adult should be encouraged to prepare Advance Directives** including the following documents:

- Living Will
- Durable Health Care Power of Attorney
- Pre-hospital Medical Care Directive
- Durable Mental Health Care Power of Attorney
- Financial Power of Attorney

There are other kinds of documents referred to as "Power of Attorney", "General Power of Attorney", "Financial Power of Attorney" and others. These may include forms about organ donation or autopsy. Samples and copies of these documents are available from a variety of sources often designed as fill-in-the-blank forms. They are legal documents and have a number of rules that may vary from state-to-state. Be sure the documents are current with changes or variations recommended for the state where the person lives as well as address special circumstances and needs.

### ❖ That's a lot of "Powers;" but what does it mean; who needs one; and, where does a Guardianship or Conservatorship fit into all this?

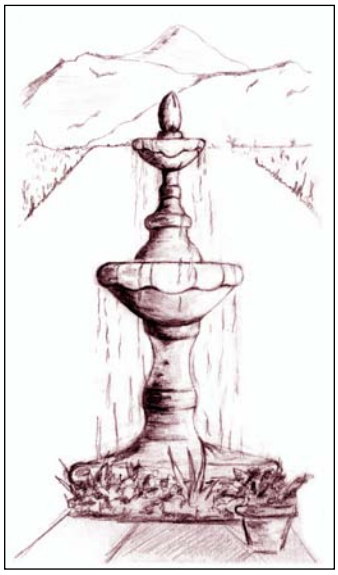
Advance Directives are documents that describe the health and/or financial preferences of the person, and identify an **"agent" (an individual authorized by the person to make decisions on their behalf under certain guidelines with or without limitations)**. The documents go into effect and the "agent" usually assumes responsibility when the person becomes incapable of communicating their needs or if suffering from an illness that affects their competency. If the person recovers and is able to communicate and make competent judgements, they regain control of their health care decisions. Preparing the above documents can prevent difficult legal court proceedings (called Guardianship and/or Conservatorship) that may become necessary if the person requires an "agent" but has become incapacitated prior to completing the required documents.

### ❖ If a person has Power of Attorney documents, why would they need to go through the Courts to obtain a Guardianship?

Power of Attorney documents are very helpful, but ONLY as long as the person agrees to cooperate. If the person has prepared these directives but chooses not to comply with the plan or decisions being made by the "agent", then it may become necessary to Petition for Guardianship to protect the person. A Guardianship is a formal court proceeding. The person must be notified of the hearing and an attorney is appointed to present their point of view to the court.
If the court finds the person unable to make or communicate responsible decisions, a Guardian or Conservator is appointed to manage the person's affairs even if they object to the decisions.

### ❖ What if the individual does not have a Health Care Power of Attorney?

If the person does not have the necessary documents and still has the capacity to understand and execute the documents, an attorney can draft them to their specifications. If the person no longer has the capacity to understand the nature of the documents then a Guardianship proceeding might be required or the Surrogate List may apply. The following individuals, if willing, can serve as Surrogate Decision Makers regarding treatment decisions for the patient (in order of priority): spouse (unless legally separated), adult child, parent, domestic partner, sibling, a close friend or the attending physician.



### ❖ What if the person wants to change their Power of Attorney or Living Will?

The maker of the document can modify their Advance Directives at any time. Also, the designated "agent" cannot delegate their responsibility to another "agent." Therefore, it is advisable to have the documents name a second party as an alternate in the event the designated “agent” is unable or unavailable to serve when needed. When changing their documents, the person should notify the selected "agent" in writing, destroy the document, notify their physician as well as any other health care providers verbally and in writing.

# DEFINITIONS OF LEGAL DOCUMENTS

*helping older relatives or friends make more informed choices about medical care and/or financial decisions*

*What is my role as a caregiver for an older relative or friend?* If you are the designated caregiver you must remember to always respect the rights and wishes of the relative or friend under your care. Ask yourself: What does my relative or friend want? How would my relative or friend decide? *You cannot just take charge without the person's permission.*

## LEGAL DOCUMENTS DEFINED

This brief description of legal documents may help you, in your caregiver role, assist family members to make more informed choices about their medical care and financial directives.

## ADVANCE DIRECTIVES

A generic term for a group of documents that are prepared prior to needing help or care. If the person is unable to communicate their health care wishes this information explains and enforces their requests. Some documents require the person designate an "agent" (an individual authorized by the person to make decisions on their behalf under certain guidelines with or without limitations) to carry out their decisions. The person signing an advance directive must be able to understand the nature of the document being signed.

## LIVING WILL

Allows the person to identify which medical procedures and interventions they want or do not want to be performed. It is used when they are unable to make their own decisions due to a terminal condition, irreversible coma or persistent vegetative state. A Living Will may be part of a Health Care Power of Attorney or a separate stand-alone document.
NOTE: It is important to ask your doctor about the meaning of all terms, treatments and the implications of your Living Will. It is intended to guide treatment decisions if the person cannot express their choices.

## DURABLE HEALTH CARE POWER OF ATTORNEY

Allows the person to choose someone (called an "agent") to make future health care decisions based on preferences expressed by the patient. It can include specific treatment protocols and limitations that direct the health care team.

NOTE: A Medical or Health Care Power of Attorney gives the "agent" authority to make medical decisions, unless the person specifically includes limitations. It only becomes effective when the person becomes too ill to make or communicate decisions. The "agent" can make decisions until the person recovers. At which time, the "agent" is no longer authorized to make decisions. Health Care Power of Attorney is revocable by its creator.

## PRE-HOSPITAL MEDICAL CARE DIRECTIVE (Do Not Resuscitate - aka "Orange Card")

Informs and permits emergency medical personnel not to resuscitate the person. By signing the Orange Card, the person has given consent to not have equipment, drugs or devices used to restart their heart or breathing. Presenting this document to emergency responders means that the person is ready to die and death may result.
NOTE: The Pre-Hospital Medical Care Directive is a standardized form that must be printed on orange paper and signed by a physician to be valid. A recent photo of the person should be attached to the form.

## DURABLE MENTAL HEALTH CARE POWER OF ATTORNEY

Allows the person to appoint an "agent" to make future mental health care decisions if unable to do so. It permits the agent to initiate some form of mental health treatment that would otherwise require client action. The Mental Health Care Power of Attorney may be revocable even if the person is incompetent.
NOTE: This document may be helpful for someone with mental illness or a disease

related dementia that may require institutional mental health services in the future. Mental health institutional placements are not covered by a regular Health Care Power of Attorney and require a court proceeding. Preparing the Mental Health Care Power of Attorney can facilitate or allow treatment without the formal court process.

## FINANCIAL POWER OF ATTORNEY

Allows the person to appoint an "agent" with the required authority to manage financial matters including business and property decisions. A Financial Power of Attorney gives the "agent" specific instructions and/or limitations only to benefit the person initiating the document. The "agent" cannot benefit from the Power of Attorney unless specifically stated in the document. Additional factors that may be considered include:

## GUARDIANSHIP

A result of a legal action requiring a court proceeding that removes decision making power from the subject of the guardianship and transfers it to the guardian. The guardian is appointed by the court to make personal decisions for the incapacitated person.

## CONSERVATORSHIP

A result of a legal action requiring a court proceeding. The appointment by the court, after a hearing, of an individual or corporation to manage the financial affairs of a person who can no longer manage his or her own property or financial matters.

## FIDUCIARY

A person who accepts the responsibility for taking care of the needs or property of another person for the benefit of that person. Public Fiduciary - A County official that has statutory responsibility for guardianship of persons who require a guardian or conservator and have no one to assume this role. Private Fiduciary - A certified or licensed Fiduciary that serves as a personal guardian or conservator.

## SURROGATE DECISION MAKERS

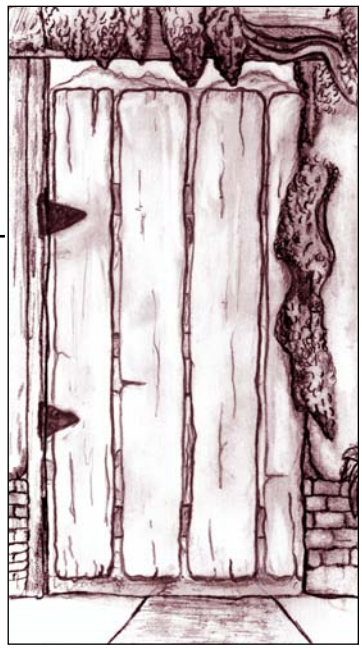
(Statute 36-3231) If the person is unable to make or communicate health care treatment decisions and has not prepared advance directives a surrogate decision maker can make health care decisions for the patient. If willing and available, the following individuals can serve as surrogates regarding treatment decisions for the patient (in order of priority): spouse (unless legally separated), adult child, parent, domestic partner, sibling, a close friend or the attending physician.

NOTE: If the patient has chosen an "agent" as a health care power of attorney or has a court appointed guardian for health care decisions they would serve as the patient's surrogate.

ALL OF THE ABOVE DOCUMENTS ARE MEANT TO BE COMMUNICATED AND SHARED WITH FAMILY MEMBERS AND APPROPRIATE PROFESSIONALS. THEY SHOULD BE STORED IN AN EASILY ACCESSIBLE LOCATION AND NOT LOCKED IN A SAFETY DEPOSIT BOX OR FILE CABINET.

# DIRECTIVAS AVANZADAS

*Ayudando a parientes o amigos envejecidos en hacer mejor decisiones informativas sobre las opciones que uno tiene de cuídado de salud y/o asuntos de finanzas.*



## PREGUNTAS QUE SURGEN PREGUNTAR FREQUENTEMENTE

Así como un cuídador, puedo ver cambios en mis seres querídos que indican que quíza es tiempo de pedir ayuda con las decisiones medicas y de finanzas pero no estoy segura(o) **donde comenzar**.

❖ **¿Donde y como comienza el cuídador cuando le preocupa la habilidad de la persona en manejar adecuadamente sus decisiones finanzeras y medicas?**

Comienze con el entendimiento que todas las personas son competentes y tienen el derecho de rechazar tratamiento o asistencia. Converse con la persona sobre este tema para determinar si esta dispuesta(o) en aceptar asistencia de usted. Si no esta dispuesta(o), preguntele si hay documentos preparados designando a alguien que esté de acuerdo en asistir a la persona con las decisiones medicas y finanzeras.

❖ **¿Que si no han preparado documentos, no recuerdan, o no pueden comunicarse?**

Consiga permiso de la persona para ponerse en contacto con miembros de familia, amigos, medicos, y su abogado personal para verificar si alguien puede asegurar la existencia de estos documentos..

❖ **¿Como el cuídador, necesito unos documentos formales para poder hacer decisiones (medicas y de finanzas) o puedo ponerme a cargo sin nada?**

**No puede ponerse encargada(o) sin el permiso de la persona.** Si la persona esta dispuesta(o) y acepta su ayuda, un cuídador puede asistir en varias maneras….pero aún hasta un cierto punto. Según el tipo de asistencia requerída, se puede necesitar una autoridad legal para hacer las decisiones. Tambien puede haber reglamentos que hagan esta tarea trabajosa sin la presencia de ciertos documentos apropiados. **El cuídador (aparte del esposo(a)) no esta obligado(a) a tomar esta responsabilidad. Es importante que el cuídador entienda la naturaleza y las consequencias asociadas en llevar a cabo esta responsabilidad.**

❖ **¿Porque necesitamos cualquier de estos documentos?**

A cualquiera edad, uno puede tener una emergencia que pueda temporalmente o permanentemente limitar su habilidad de comunicarse oralmente o **indicar** su preferencia de tratamiento. Tambien cada uno de nosotros tenemos variedad de creencias culturales, personales y religiosas que pueden influír nuestras decisiones. Es importante de comunicar nuestras creencias a alguien que nos conosca bien y que hable de parte de nosotros si ya no podemos hacer decisiones medicas, finanzeras y otras decisiones importantes. Es muy importante que esta persona defienda nuestras creencias aunque no sean las creencias de ella (o él) misma. Documentos que dan la oportunidad de declarar como y que tipo de tratamiento la persona quiere antes de necesitarse son conocidos como "Directivas Avanzadas." **Todos los adultos deben ser inculcados de preparar Directivas Avanzadas** incluyendo los documentos seguientes:

- Testamento Mientras Vivo *(Living Will)*
- Poder Durable Del Cuídado De Salud (Durable Health Care Power of Attorney)
- Directivas de Cuídado Medico Antes de Hospitalizar
  (Pre-Hospital Medicare Care Directives)
- Poder Durable Del Cuídado de Salud Mental
  (Durable Mental Health Care Power of Attorney)
- Poder De Finanzas (Financial Power of Attorney)

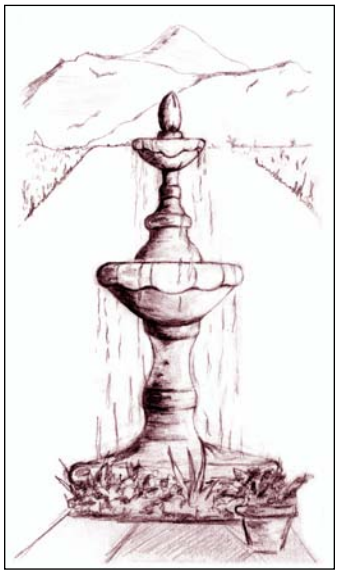
Hay otras clases de documentos conocidos como "Poder", "Poder General", "Poder De Finanzas" y otras más. Estos otros pueden ser formas de la donación de órganos o autopsia. Ejemplares y reproducciones de estos documentos se pueden obtener de varios recursos muchas veces diseñados como para solo llenar las partes blancas. Son documentos legales y tienen numerosas reglas que pueden cambiar de estado a estado. Asegure que los documentos esten al corriente con los cambios o la variedad recomendada por el estado donde la persona vive y incluír anotaciones de cualquier circumstancia o necesidad especial.

### ❖ Eso son muchos "Poderes" pero ¿que es lo que significan?; ¿quien necesita de ellos?; y ¿donde merece estar una Tutela o Guardián en todo esto?

Directivas Avanzadas son documentos que explican las preferencias de salud y/o de finanzas de la persona y identifican un **"agente" (una persona autorizada por la persona para que haga las decisiones de su parte bajo ciertas direcciones con o sin limitaciones)**. Los documentos se llevan a cabo y el "agente" se toma cargo de sus responsabilidades cuando la persona este incapacitada de comunicar sus necesidades o sufre de una enfermedad que afecta su capacidad. Si la persona se recupera y puede comunicarse y hacer decisiones competentemente, pueden conseguir de nuevo el control de todas sus decisiones sobre su salud. Cuando se preparan estos documentos con anticipo se evita tener procedimientos legales dificultosos (conocidos como Tutelas y Guardianes) que pueden ser necesarios si la persona se queda incapacitada y requiere un "agente" antes de terminar los documentos requeridos.

### ❖ ¿Si la persona tiene documentos de Poder, porque necesitan de un tribunal para obtener un Guardian?

Los documentos de Poder son muy útil pero SOLO si la persona esta de acuerdo de cooperar. Si la persona ha preparado esta directiva pero prefiere no cumplir con el plan o las decisiones hechas por el "agente", entonces puede ser necesario someter una "Petición de Guardián" para proteger esa persona. Esta petición de guardián se lleva a cabo como un procedimiento legal ante un tribunal. La persona se le debe notificar de la audiencia ante el tribunal y un abogado se le nombrara para presentar su punto de vista ante el tribunal. Si el tribunal determina que la persona no puede hacer o comunicar sus decisiones responsablemente, entonces se le nombra un Guardián o Tutela para que maneje los asuntos de la persona aunque la persona se oponga a las decisiones.



### ❖ ¿Que si la persona no tiene un Poder De Cuídado De Salud?

Si la persona no tiene los documentos necesarios y todavía mantiene la capacidad de entender y otorgar los documentos, un abogado los puede apuntar con sus detalles. Si la persona ya no es capaz de entender la naturaleza de los documentos entonces se puede requerer un procedimiento para escoger un Guardián o se puede aplicar la lista de sustitución. Los seguientes individuos, si gustan, pueden ser sustitutos para hacer decisiones con respeto a tratamientos de parte de la persona (en orden de prioridad):

cónyuge (a menos que esten separados), hijo(a) adulto, padre, compañero(a) domestico, hermano(a), un amigo inmediato o el medico atendiendo el paciente.

❖ **¿Que si la persona gusta cambiar su Poder o su Testamento Viviente?**

La persona que hace el documento puede modificar o cambiar sus Directivas Avanzadas a cualquier tiempo. Tambien, el "agente" encargado no puede delegar sus responsabilidades a otro "agente". Se recomienda que los documentos nombren a una segunda persona como sustituto en caso que el "agente" encargado no pueda o no este disponible a servir cuando se necesita. Cuando cambien sus documentos, la persona debe hacer lo siguiente: avisar por escrito al "agente" seleccionado, debe destruír los documentos, debe avisar a su medico asi como cualquier proveedor de cuídado de salud por escrito y oralmente.

## RECURSOS

**Información con mas detalle sobre las Directivas Avanzadas se pueden conseguír gratis en:**

**Pima Council on Aging**
8467 E Broadway Blvd.
Tucson Arizona 85710-4009
(520)790-7262
www.pcoa.org

**Arizona Office of the Attorney General**
Life Care Planning Information & Documents
(602)542-2124
www.ag.state.az.us

**Federal Trade Commission**
www.ftc.gov/bcp/menu-seniors.htm
Toque el botón: Aging Parents and Adult Children Together

**Para localizar un abogado que pueda ayudar a preparar o revisar sus Directivas Avanzadas, pongase en contacto con:**

**National Academy of Elder Law Attorneys**
1604 N Country Club Road
Tucson Arizona 85716
www.naela.com
(520) 881-4005

*Este folleto es preparado para el Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro De Envejecimiento De Arizona (Arizona Center on Aging) de la Universidad de Arizona®*

# DEFINICIONES DE DOCUMENTOS LEGALES

*Ayudando a parientes o amigos envejecidos escoger las mejores opciones delatadas sobre su atención medica y/o decisiones financieras*

*¿Qué es mi papel como cuídador de un pariente o amigo envejecido?* Si es usted el cuídador designado, debe recordar siempre de respetar los derechos y deseos del pariente o amigo bajo su cargo. Preguntese: ¿Qué es lo que mi pariente o amigo gusta? ¿Como puede decidir mi pariente o amigo? *Usted no debe de ninguna manera ponerse en cargo sin el permiso de esa persona.*

## DOCUMENTOS LEGALES DEFINIDOS

Estos documentos legales brevemente detallados pueden ayudarle en su papel de cuídador para asistir a miembros de familia escoger las mejores opciones delatadas sobre sus propias atenciones medicas y directivas financieras.\

## DIRECTIVAS AVANZADAS

(Advance Directives)

Este es un termino generico para un grupo de documentos que son preparados antes de necesitar ayuda o cuídado. Si la persona no puede comunicar sus deseos de cuídado de salud, esta información explica y ejecuta sus encargos. Algunos documentos requieren que la persona indíque un "agente" (un individuo autorizado(a) por la persona para hacer decisiones de su parte bajo ciertas guíanzas con o sín limites) que sostenga sus decisiones. La persona que firma esta directiva avanzada debe entender por completo la naturaleza del documento que esta firmando.

## TESTAMENTO VIVIENTE

(Living Will)

Permite la persona que indíque cual procedímiento medico y intervenciones que gustan o no gustan que pueden ser a cabo. Son ocupadas cuando la persona no puede hacer sus propias decisiones debido a una condición terminal, coma irrevisible o un estado vegetativo persistente. Un Testamento Viviente puede ser parte de un "Poder" para el cuídado de salud o un documento solo y separado.

ANOTACION: *Es muy importante que le pregunte a su medico o doctor sobre el significado de todos los terminos, tratamientos y las implicaciones sobre su Testamento Viviente. La intención de este documento es solo para guíar sus decisiones de tratamiento si a caso la persona no puede expresar sus preferencias.*

## PODER DURADERO PARA EL CUIDADO DE SALUD

(Durable Health Care Power of Attorney)

Permite la persona que escoja alguién (llamado "agente") que haga decisiones del cuídado de salud en el futuro basadas en las preferencias que el paciente haga indicado. Puede incluír el protócolo de ciertos tratamientos específicos y las limitaciones que ordenen el equípo de cuídado de salud.

ANOTACION: *El Poder Para El Cuídado De Salud o el cuídado medico dá al "agente" la autoridad de hacer decisiones medicas al menos que la persona incluya limitaciones específicas. Solo puede ser realizado cuando la persona se enferme tanto como para no poder hacer o comunicar sus decisiones. El "agente" puede hacer las decisiones hasta que la persona se recupere. Al cual tiempo el "agente" rendira su autorización de hacer las decisiones. El Poder Para El Cuídado de Salud es revocable por el creador.*

## DIRECTIVA DEL CUIDADO MEDICO ANTES DE HOSPITALIZAR

(No Resucitar – tembien conocido como "La Carta Anaranjada" <Orange Card>)

Informa y permite el personal emergente medico de NO resucitar la persona. Firmando "La Carta Anaranjada," la persona a dado consentimiento de NO utilizar equípo, drogas o aparatos para comenzar de nuevo el corazon o su respiración. Presentando este documento al personal emergente respondiendo, significa que la persona esta dispuesta(o) a morir y la muerte puede resultar.

ANOTACION: *La Directiva Del Cuídado Medico Antes De Hospitalizar es una forma normalizada que debe ser imprimida en papel anaranjado y ser firmada por un medico para que sea valida. Una foto reciente de la persona debe ser adherida a la forma.*

## EL PODER DURABLE DEL CUIDADO DE SALUD MENTAL

(Durable Mental Health Care Power of Attorney)

Permite que la persona escoga un "agente" que pueda hacer las decisiones en el futuro sobre el cuídado de salud mental si uno no esta disponible. Permite el agente que inicie alguna forma de tratamiento de salud mental que al contrario requierá acción del cliente. El Poder Del Cuídado De Salud Mental puede ser revocable aún que la persona este incompetente.

ANOTACION: *Este documento puede ser útil para alguién con enfermedad mental o una enfermedad relacionada a la demencia que requiera en el futuro los servicios de una institución de salud mental. La colocación en una institución de salud mental no es parte de un Poder de Cuídado de Salud regular y se requiere el procedimiento por un tribunal. La preparación de un Poder de Cuídado de Salud Mental puede facilitar o permitir el tratamiento sin el procedimiento formal de un tribunal.*

## PODER DE FINANZAS

(Financial Power of Attorney)

Permite que la persona nombre un "agente" con la autorización necesaria para manejar asuntos financieros incluyendo decisiones de negocio y propiedad. El Poder De Finanzas otorga al "agente" instrucciones y/o limitaciones específicas solo para beneficiar a la persona iniciando el documento. El "agente" no es permitido beneficiar del Poder al menos que sea específicamente declarado en el documento.

Factores Adicionales Que Puedan Ser Considerados Incluye:

## GUARDIAN

El resultado de una elección por un tribunal despues de una audiencia que quíta todo el poder de decisiones de un propio sujeto y translada el poder a un guardián. El guardián es otorgado el Poder de hacer decisiones personales para la persona incapacitada.

## CONSERVADOR

El resultado de una acción legal requeriendo el procedímiento de un tribunal. La elección por un tribunal, despues de una audiencia, de una persona individual o una corporación para que mantenga los asuntos financieros de una persona que no puede seguír manteniendo sus propiedades o sus negocios financieros.

## FIDUCIARIO

Una persona que acepta la responsabilidad de cuídar las necesidades o propiedades de otra persona para el beneficio de esa persona. Fiduciario Público – Un oficial del condado que tiene responsabilidad reglamentaria de guardián para aquellas personas necesitando un guardián o conservador y que no tengan a agluien que pueda tomar este papel. Fiduciario Privado: Un fiduciario que tenga certificación o licensia y que sirve de guardián personal o conservador.

## VICARIO DE DECISIONES

(Reglamento 36-3231) Si la persona no puede hacer o comunicar sus decisiones sobre tratamiento del cuídado de salud y no ha preparado directivas avanzadas, un Vicario De Decisiones puede hacer esas decisiones del cuídado de salud para el paciente. Si estan dispuestos y disponibles, las siguientes personas pueden llevar el papel de Vicario sobre las decisiones de tratamiento para el paciente (en orden de prioridad): cónyuge (al menos que esten separados legalmente), hijo(a) adulto, padres, compañero(a) domestico, hermano(a), un amigo(a) inmediato o el medico atendiendo al paciente.

ANOTACION: *Si el paciente a escogido un "agente" como su Poder de Cuídado de Salud o tiene un guardián seleccionado legalmente por la corte para hacer las decisiones sobre el cuídado de salud, esta persona servirá de Vicario para el paciente.*

TODOS LOS DOCUMENTOS MENCIONADOS DEBEN SER COMUNICADOS Y COMPARTIDOS CON MIEMBROS DE FAMILIA Y PROFESIONALES ADECUADOS. ESTOS DOCUMENTOS DEBEN SER GUARDADOS EN UN LUGAR QUE SEA FACILMENTE ACCESIBLE Y NO SE DEBEN ENCERRAR EN UNA CAJA DE SEGURIDAD NI EN UN GABINETE DE ARCHIVAR.

# INFORMED CARE PLANNING

*helping older relatives or friends plan and make informed decisions about their future care*

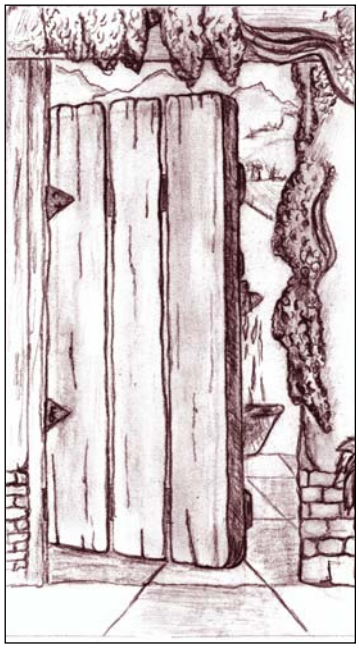
## MAKING INFORMED DECISIONS

As a family caregiver, it is likely that your older relative relies on you and other family members to help plan for their future. In this role, it is important to identify problems that may exist, assess what may be needed and gather the most relevant information so that together you and your relative can make the best possible decisions about their current and future care.

## ASSESSING WHAT IS NEEDED

Caregivers as well as loved ones can feel anxious, worried and confused at times. Although you recognize that you must take action and do "something", it may be difficult to actually do it. These "blocks" may prevent you from following through on what needs to be done in a specific situation. Some suggestions for overcoming these feelings and determining what is needed are:

- **Try not to make important decisions while you are upset.** Sometimes you must make a decision immediately but often you don't have to. If the situation requires an immediate decision it becomes important to have vital information about your loved one prepared in advance, such as: date of birth, social security number, Medicare number, health insurance policy numbers, health conditions and allergies, current medications, names and telephone numbers of treating physicians and copies of advance directives, if any. Searching for information when you and your loved one are in a crisis situation will make a difficult situation more stressful.
- **Take time to sort things out.** Try to make sense of the situation, by asking yourself: "What is really happening here?" It may be helpful to make a list. Divide a piece of paper into three columns; in the first column identify the problems as well as your own limitations. In the second column, list your relative's needs and your needs as a caregiver. Then identify where to seek information and advice in the third column. Also, asking yourself the following questions may be of help:
- What are my relative's wishes and preferences for their future care?
- Will my relative be willing to accept assistance from others (friends, family members and/or professionals)?
- Who among family members and friends will be able and willing to help? What type of contributions can they make to the care of the loved one?
- Who among family members and friends is my relative most likely to trust?
- Is professional help needed? How do I match the help needed with my family care situation?
- How much money is available to put toward the care needed?
- **Talk over important problems with persons you trust.** If you and your relative feel unable to pinpoint what you really need then ask a friend, another family member and/or seek professional advice. You may know only that you feel stressed and unable to handle the situation. If that is the case, call Pima Council on Aging (Ph: 790-7262) and ask for the Caregiver Specialist and/or the Caregiver Education and Support Program (Ph: 546-4481 or 546-4482). Staff will help you identify the problem and understand the care options that are available for you and your relative.



## STEPS IN THE CARE PLANNING PROCESS

Promoting good care planning means helping your loved one make better choices, solve problems and improve their under-standing of alternative care options. Steps involved in the care planning process are:

- Become aware of and identify a problem: What it is and why it is happening?
- Search and gather information from various sources to help when considering support services and programs. For example: public libraries have numerous guides and pamphlets available for helping caregivers select services and programs, computer Internet Websites (computers for public use are available at all local

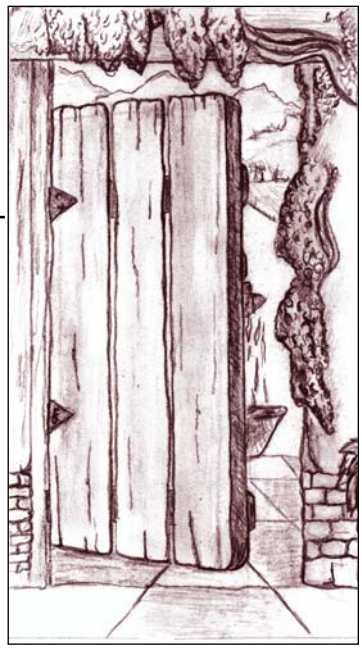
libraries), and local agencies (i.e., Pima Council on Aging and the Caregiver Education and Support Program) are very helpful. Also, talking with other people who have had similar experiences will help you determine what questions to ask, identify resources and other possibilities. Remember all questions are important and you have a right to information about all service providers.

- Evaluate care alternatives. Discuss possible alternatives with your loved one and other family members. Once you have narrowed the choices compare them with what matters most to your loved one (i.e., independence, comfort, costs, location).
- Choose a course of action and develop a strategy. You should consider developing a "back-up" plan in case your original strategy proves to be unsatisfactory.
- Evaluate the results and determine if a satisfactory solution was obtained. Did it meet your goals and expectations? If not, ask yourself: Can you and your relative live with the results or do you need to make changes to better accommodate your relative's needs and wishes?

The care planning process may help you and your loved one make informed decisions about their current and future care as well as guide your selection and use of support services and programs. Keep in mind, that by accepting paid services, you are not replacing but only supporting and strengthening the informal help currently provided by family and friends.

# INFORMED CARE PLANNING

*helping older relatives or friends plan and make informed decisions about their future care*



## FREQUENTLY ASKED QUESTIONS ABOUT HOW TO MAKE GOOD DECISIONS

As a family caregiver you willingly offer your loved one comfort, support and assistance to maximize their well-being. It is likely that your older relative relies on you and other family members to help solve real-life everyday problems as well as plan for the future. In this role, it is important to identify problems that may exist, assess what may be needed and gather the most relevant information so that together you and your relative can make the best possible decisions about their current and future care.

### ❖ I feel overwhelmed and at a loss. I think my loved one needs care beyond what I am providing as a family caregiver. How do I begin? What are my options?

Caregivers as well as loved ones can feel anxious, worried and confused at times. Throughout your caregiving journey you will want to adjust to your changing needs as well as those of your loved one. Although you recognize that you must take action and do "something", it may be difficult to actually do it. These "blocks" may prevent you from following through on what needs to be done in a specific situation. Some suggestions for overcoming these feelings are:

- **Try not to make important decisions while you are upset.** Sometimes you must make a decision immediately but often you don't have to. If the situation requires an immediate decision it becomes important to have vital information about your loved one prepared in advance, such as: date of birth, social security number, Medicare number, health insurance policy numbers, health conditions and allergies, current medications, names and telephone numbers of treating physicians and copies of advance directives, if any. Searching for information when you and your loved one are in a crisis situation will make a difficult situation more stressful.
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    - Who among family members and friends will be able and willing to help? What type of contributions can they make to the care of the loved one?
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- **Talk over important problems with persons you trust.** If you and your relative feel unable to pinpoint what you really need then ask a friend, another family member and/or seek professional advice. You may know only that you feel stressed and unable to handle the situation. If that is the case, call Pima Council on Aging (Ph: 790-7262) and ask for the Caregiver Specialist and/or the

Caregiver Education and Support Program (Ph: 546-4481 or 546-4482). Staff will help you identify the problem and understand the care options that are available for you and your relative.

❖ **I lack the knowledge and confidence I need to help my relative make informed choices about their care. I want to make sure I understand what is involved in the care planning process.**

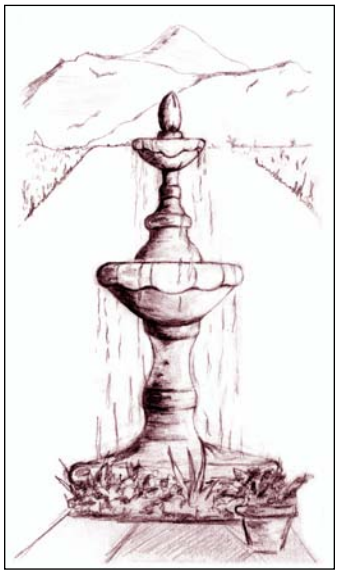
Promoting good care planning means helping your loved one make better choices, solve problems and improve their understanding of alternative care options. People make decisions based on a range of factors, such as: cultural values and traditions, family relationships, friend's suggestions, emotions, attitudes, personal characteristics, past experiences and perceptions. Steps involved in the care planning process are:

- Become aware of and identify a problem: What it is and why it is happening?
- Search and gather information from various sources to help when considering support services and programs. For example: public libraries have numerous guides and pamphlets available for helping caregivers select services and programs, computer Internet Websites (computers for public use are available at all local libraries), and local agencies (i.e., Pima Council on Aging and the Caregiver Education and Support Program) are very helpful. Also, talking with other people who have had similar experiences will help you determine what questions to ask, identify resources and other possibilities. Remember all questions are important and you have a right to information about all service providers.
- Evaluate care alternatives. Discuss possible alternatives with your loved one and other family members. Once you have narrowed the choices compare them with what matters most to your loved one (i.e., independence, comfort, costs, location).
- Choose a course of action and develop a strategy. You should consider developing a "back-up" plan in case your original strategy proves to be unsatisfactory.
- Evaluate the results and determine if a satisfactory solution was obtained. Did it meet your goals and expectations? If not, ask yourself: Can you and your relative live with the results or do you need to make changes to better accommodate your relatives needs and wishes?

The care planning process may help you and your loved one make informed decisions about their current and future care as well as guide your selection and use of support services and programs. Keep in mind, that by accepting paid services, you are not replacing but only supporting and strengthening the informal help currently provided by family and friends.

## RESOURCES

- Pima Council on Aging
  8467 E. Broadway Blvd.
  Tucson, Arizona 85710-4009
  Phone: (520) 790-7262
  www.pcoa.org
- Caregiver Education and Support Program
  2250 N. Craycroft, Suite 250
  Tucson, Arizona 85712
  Phone: (520) 546-4481 or 546-4482
  caregivers@pimahealthsystem.org
- Caregiver Consortium
  www.arizonacaregivers.org
- National Association for Home Care
  Phone: (202) 547-7424 or www.nahc.org

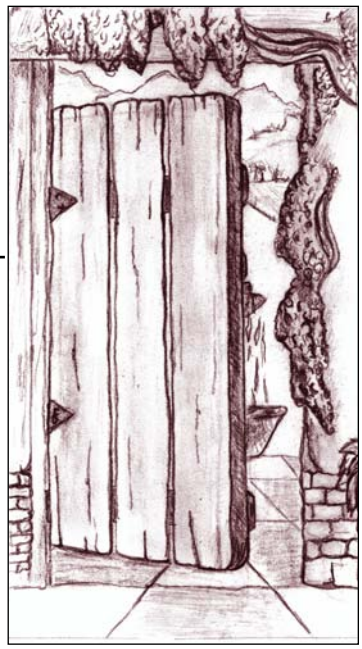


- National Council on the Aging
  www.benefitscheckup.com
- Family Caregiver Alliance
  Phone: (415) 434-3388 or www.caregiver.org
- Administration on Aging
  www.aoa.gov/caregivers/default.htm
- AARP LifeAnswers
  www.aarplifeanswers.com
- National Adult Day Services Association
  Phone: (202) 479-6682
  (how to select a day program)
  www.ncoa.org/nadsa/guide_2_ADS.htm or
  (how to find a local day program) www.nasda.org
- CareGuide Assessment
  (a set of questions designed to help you prioritize your areas of concern about appropriate resources for your elder care situation) at:
  www.careguide.com
  Click on: Featured Topics
- Evaluating & Selecting a Care Provider or Facility
  www.careguide.com
  Click on: Featured Topics
- How to Research Care
  www.careguide.com
  Click on: Featured Topics
- Living Alternatives
  www.careguide.com
  Click on: Living Alternatives
- Eldercare Locator
  www.eldercare.gov/
- Housing Options for Older Americans
  www.aoa.gov/factsheets/housing.html
- Choosing a Nursing Home (AARP)
  www.aarp.org/confacts/health/choosingnh.html
- Caregiving: Involving Others
  www.aarp.org/confacts/caregive/others.html
- Talking About Independent Living
  www.aarp.org/confacts/caregive/indliving.html
- Out-of Home Options: The Residential Care Continuum at:
  www.careguide.com
  Click on: Living Alternatives, select: Related Articles

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# PLANIFICACION DE CUIDADO INFORMADO

*Ayudando a parientes y amigos envejecidos planear y hacer decisiones informadas de su cuídado futuro*



## PREGUNTAS QUE SURGEN PREGUNTAR FRECUENTEMENTE SOBRE COMO HACER LAS MEJORES DECISIONES EN PLANIFICAR EL CUIDADO DE UN PARIENTE ENVEJECIDO

Como un cuídador familiar, usted le ofrece a su pariente de buena voluntad toda las comodidades, apoyo y asistencia para máximar el bien-estar de su pariente. Es por está razón que probablemente su pariente cuenta con usted y los otros miembros de su familia para ayudar resolver los problemas diarios de la vida real así como planear el futuro. En este papel, es importante identificar los problemas que pueden existir, calcular qué es lo que se pueda necesitar, y juntar la información más pertinente para que juntos, usted y sus parientes, puedan hacer las mejores decisiones posible de su cuídado presente y futuro.

❖ **Me siento agobiado y perdido. Pienso que el cuídado que mi ser querido necesita es más de lo que yo puedo ofrecerle como cuídador de familia. ¿Cómo comienzo? ¿Qué son mis opciones?**

Cuídadores así como seres queridos, pueden sentirse a veces inquietos, preocupados y confudidos. Durante su trayecto como cuídador, usted tendra que ajustarse a sus cambios necesarios así como los de su ser querido también. Aunque usted reconozca que debe tomar acción y hacer ”algo”, puede ser difícil hacer ésto en realidad. Estos obstáculos pueden prevenirlo en hacer lo qué se debe en ciertas situaciones especificamente. Algunas sugerencias para poder sobresalir de esto:

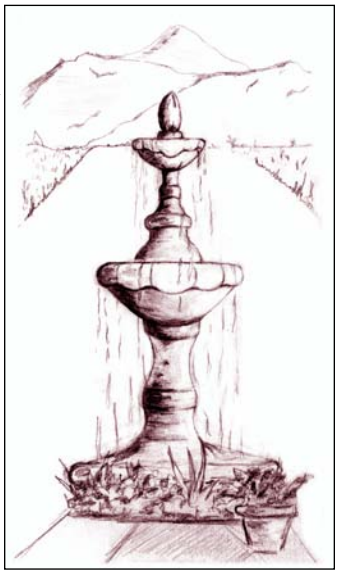
- **Trate de no hacer decisiones importantes por mientras que permanezca molesto.** Hay veces que uno tiene qué hacer decisiones inmediatas pero frecuentemente ésto no es el caso. Si la situación exige una decisión inmediata, es muy importante tener toda la información vital de su pariente preparada antemano, así como: fecha de nacimiento, número de seguro social, número de “Medicare”, número de la póliza de seguro de salud, condiciones de salud y alergias, medicamentos que toma presente, nombres y números de teléfono de todos los médicos que atienden ahora a su pariente y las copias de las directivas avanzadas, si hay. Tener que buscar esta información cuando usted y su ser querido se encuentran en una situación crítica, hace una situación díficil más tensa.
- **Tome el tiempo para surtir las cosas.** Trate de razonar la situación. Preguntese: “¿Qué es lo que realmente está pasando aquí?” Puede ser útil hacer una lista. Separe una hoja de papel entre tres columnas; en la primera columna identifiqué los problemas así como su propias limitaciones. En la segunda columna, apunte las necesidades de su pariente y sus propias necesidades como cuídador. En la tercera columna, apunte donde puede conseguír la información y consejos. También, le pueden ayudar preguntar las seguientes preguntas:
    - ¿Qué son los deseos y preferencias de mi pariente para su cuídado futuro?
    - ¿Está mi pariente dispuesto acceptar ayuda de otros (amigos, miembros de familia y/o profesionales)?
    - ¿Quién entre nuestros miembros de familia y amigos pueden y estaran dispuestos a ayudar? ¿Qué tipo de contribución pueden hacer al cuídado de mi ser querido?
    - ¿Quién entre nuestros miembros de familia y amigos puede mi pariente tenerles confianza?
    - ¿Se necesita ayuda profesional? ¿Cómo puedo combinar la ayuda que se necesita con mi situación de ayuda familiar?

- **Hable con personas que usted confie de problemas importantes.** Si usted y su pariente no se sienten capaz de ser precisos de lo que realmente necesitan, preguntele a una amistad, otro miembro de familia y/o consulte con un profesional. Ustedes pueden saber solo que se sienten tensos y sin manera de enfrentar la situación. Si es esto el caso, entonces llame al Concilio de Envejecimiento de Pima ("Pima Council on Aging), al número de teléfono 790-7262 y pregunte por el especialista de cuídadores ("Caregiver Specialist") y/o el programa de educación y apoyo de cuídadores ("Caregiver Education and Support Program") al número de teléfono 546-4481 o 546-4482. El personal de ahí le ayudaran identíficar el problema y comprenderán las opciones de cuídado que están disponibles a usted y su pariente.

## ❖ No tengo el conocimiento y la seguridad que necesito en ayudar a mi pariente para hacer selecciones informadas de su cuídado. Quiero estar seguro de entender las implicaciones del proceso de planear el cuídado.

Promoviendo la planificación de un buen cuídado significa ayudar a su ser querido hacer mejor decisiones, resolver problemas, y mejorar el entendimiento de las alternativas que hay como opciones de cuídado. Gente hace decisiones bajo una serie de factores así como: valores y tradiciones culturales, relaciones de familia, consejos de amistades, emociones, actitudes, , características personales, experiencias y percepciones del pasado. Unos pasos que tienen que ver con el procedimiento de planificar el cuídado:

- Tome en cuenta y identifiqué el problema: ¿Qué es y porqué esta pasando?
- Busque y reuna información de varios recursos para ayudar en la consideración de los programas y servicios de apoyo. Por ejemplo: las bibliotecas públicas tienen varios guías y folletos disponibles para ayudar a los cuídadores escoger servicios y programas, sitios electronicos de computadora ("Internet Websites") (hay computadoras para el uso público en todas las bibliotecas locales) y agencias locales (por ejemplo: el Concilio de Envejecimiento de Pima ["Pima Council on Aging"], y el programa para la educación y apoyo para el cuídador ("Caregiver Education and Support Program") son muy útil. También, hablando con otras personas que han precensiado experiencias similares le ayudara determinar qué preguntas hacer, identíficar recursos y otras posibilidades. Recuerde, todas las preguntas son importante y usted tiene el derecho a la información de los servicios de todos los proveedores.
- Evalue todas las alternativas de cuídado. Discuta las alternativas posible con su ser querido y otros miembros de familia. Cuando disminuya las posibilidades, comparelos con lo qué más le importa a su ser querido (por ejemplo: independencia, comodidad, costo, lugar).
- Escoja una dirección de acción y desarolle una estrategia. Usted debe considerar desarollar un plan de reserva en caso que la estrategia original resulte insatisfactoria.
- Evalue los resultados y determine si se logro una solución satisfactoria. ¿Se cumplieron los metas y expectaciones? Si no, preguntese: ¿Puede usted y su pariente vivir con estos resultados o deben hacer cambios para poder complacer mejor las necesidades y deseos de su pariente?



El proceso de una planificación de cuídado pueden ayudarle a usted y a su pariente hacer decisiones más informativas de su cuídado presente y futuro así también como guíar su selección y uso de servicios y programas de apoyo. Tome en cuenta, cuando uno acepta los servicios de paga, usted no esta reemplazando pero solo apoyando y reforzando el cuídado informal que se está extendiendo ahora por familia y amistades.

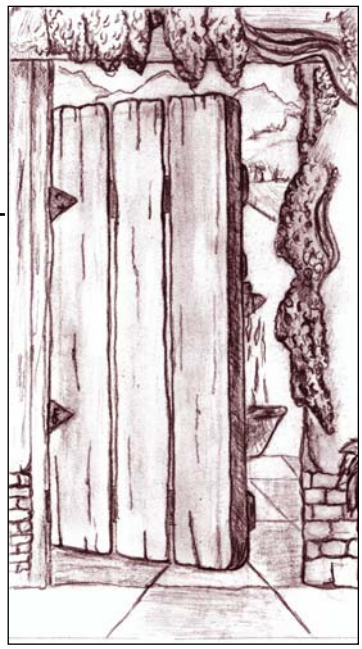
# RECURSOS

- El Concilio de Envejecimiento de Pima ("Pima Council on Aging"), 8467 E. Broadway Blvd., Tucson, Arizona 85710-4009; Teléfono: (520) 790-7262; www.pcoa.org
- El Programa de Educación y Apoyo Para Cuídadores ("Caregiver Education and Support Program"), 2250 N. Craycroft, Suite 250, Tucson AZ 85712; Teléfono: (520)546-4481 o 546-4482; disponible electrónicamente en el "Internet" caregivers@pimahealthsystem.org
- El Consorcio de Cuídadores ("Caregiver Consortium"); disponible electrónicamente en el "Internet"www.arizonacaregivers.org
- La Asociación Nacional De Cuídado En Casa ("National Association for Home Care"), Teléfono (202)547-7424 o disponible electrónicamente en el "Internet"www.nahc.org
- El Concilio Nacional de Envejecimiento ("National Council on the Aging"), disponible electrónicamente en el "Internet" www.benefitscheckup.com
- La Alianza de Cuídadores de Familia ("Family Caregiver Alliance"); Teléfono: (415)434-3388 o disponible electrónicamente en el "Internet"www.caregiver.org
- La Administración de Envejecimiento ("Administration on Aging"); disponible electrónicamente en el "Internet"www.aoa.gov/caregivers/default.htm
- Respuestas De La Vida por la Asociación de Personas Americanas Jubiladas ("AARP Life Answers"); disponible electrónicamente en el "Internet" www.aarplifeanswers.com
- La Asociación Nacional de Servicios de Día para Adultos ("National Adult Day Services Association") Teléfono: (202)479-6682; (cómo escoger un programa de día) disponible electrónicamente en el "Internet" www.ncoa.org/nadsa/guide_2_ADS.htm o (cómo hayar un programa local de día) www.nasda.org
- Guía de Evaluación para el Cuídado ["CareGuide Assessment"] (son un grupo de preguntas con la intención de ayudarle a detallar la prioridad de las areas que le preocupan sobre los recursos apropiados para la situación de cuídado de su ser querido envejecido) ; disponible electrónicamente en el "Internet" www.careguide.com y toque: "Featured Topics"
- La Evaluación y Selección de un Proveedor y Instalación de Cuídado; disponible electrónicamente en el "Internet" www.careguide.com/ y toque: "Featured Topics"
- Cómo Investigar el Cuídado; disponible electrónicamente en el "Internet" www.careguide.com/ y toqué: "Featured Topics"
- Alternativas de Viviendas; " disponible electrónicamente en el "Internet"www.careguide.com/ y toque: "Living Alternatives"
- Servicios de "Eldercare Locator"; disponible electrónicamente en el "Internet"www.eldercare.gov/
- Opciones de Alojamiento para Americanos Envejecidos; disponible electrónicamente en el "Internet"www.aoa.gov/factsheets/housing.html
- Seleccionando un Asilo de Ancianos (Patrocinado por la Asociación de Personas Americanas Jubiladas (AARP); disponible electrónicamente en el "Internet" www.aarp.org/confacts/health/choosingnh.html
- Cuídando: Dejar Otras Personas Tomar Parte; disponible electrónicamente en el "Internet"www.aarp.org/confacts/caregive/others.html
- Conversando de Vivir Independiente; disponible electrónicamente en el "Internet" www.aarp.org/confacts/caregive/indliving.html
- Opciones Fuera Del Hogar: La Continuación de Cuídado Residencial ("Out-of Home Options: The Residential Care Continuum") disponible electrónicamente en el "Internet"www.careguide.com/ y toqué: "Living Alternatives" y seleccione: "Related Articles"

*Preparado para El Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

# MANAGING CARE HELPERS IN THE HOME

*helping older relatives or friends prepare, supervise and plan for paid and/or volunteer help in the home*



## FREQUENTLY ASKED QUESTIONS ABOUT MANAGING CARE HELPERS

Being a family caregiver is not about doing it all yourself. It is about making sure your relative's needs are met. In this role, there may come a time when you and your relative decide to start using help beyond what family and friends can provide. This decision must be made with your relative when possible, based on informed choices among available home care options, good judgement and fitting a service to your family care situation. The next step, after hiring a paid caregiver or arranging for volunteer help, is to prepare yourself and your relative to share their home and supervise the daily care being provided. The following information will help guide you in the successful management of home care helpers.

### ❖ What should my relative and I expect to gain from having paid or volunteer help come into the home?

You should start with having realistic expectations of what the service can and cannot offer. Homemakers don't give baths and usually home health aides don't clean. You may have to train the care helpers to perform tasks the way you or your relative likes to have them done. Be aware that the same helper may not be available all the time depending on schedules, time-off and illness. Benefits to your relative may include companionship; different approaches to care leading to favorable results in health, functioning and behavior; and overall improved happiness and well-being. Benefits to you as the caregiver may include: respite/personal time; reduced stress; transportation for your relative to medical appointments and recreational activities; learning new caregiving skills; peace of mind; and a better relationship with your loved one.

### ❖ What type of information should I gather that would help the caregiver understand my relative's needs, likes and dislikes?

Begin by creating a **Personal Profile** of your relative. Write down information in the following areas:

- **Names** – the name your relative prefers to be called, names of family members, where they live and how they contribute to your relative's care.
- **Health** - medical conditions, treatments, medications, allergies, status of vision/hearing/speech and aids used, and the location of advance directives, if applicable.
- **Eating/Drinking Preferences** - dietary restrictions, if any.
- **Daily Routines** - waking, sleeping, meal/snack times, exercise times and type of activities, best time of day, most difficult time of day.
- **Getting Around** - right/left handed, assistive devices used (canes, walkers, wheelchair), assistance needed both inside and outside of home, transportation used to medical/professional appointments.
- **Assistance/Supervision Needed with Daily Activities** - eating, dressing, grooming, bathing, etc.
- **Activities/Hobbies** – description of activity as well as time of day performed.
- **Emergency Contacts** - names and telephone numbers of: family members and friends, treating physicians, pharmacy(s) used, health insurance information, emergency medical department preference and poison control.

Make a copy of this information for all helpers involved in your relative's care. Care helpers must know what to expect.

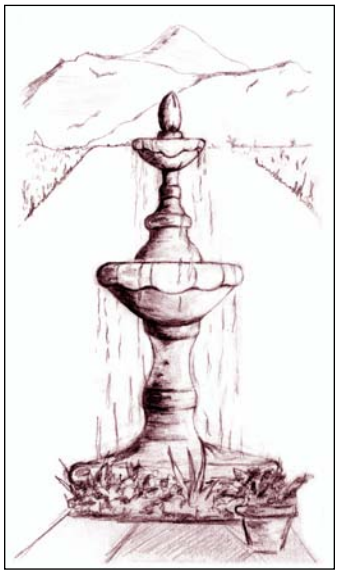
### ❖ What questions should I ask to make sure the care helper understands what my relative and I need?

What you are looking for in home care is trustworthiness, reliability, dependability, skills, good-natured care and patience. You and your relative will need to observe and evaluate the helper. Consider asking yourself the following questions:

- Is the care helper compassionate, professional, calm and proud of their work?
- Is the care helper trained in first aid and other appropriate care techniques?
- If your relative has a Prehospital Medical Care Directive (orange card and page), does the care helper understand the terms of the directive and is willing to abide by them?
- What can the care helper do to help us now?
- Is the person willing to abide by household rules? (Smoking restrictions, TV or telephone use)
- What will happen if the helper has an emergency, is sick and/or unable to arrive at their scheduled time? Are there prearranged times when the care helper will not be available? Have they planned for problems with transportation, childcare, etc?
- What arrangements need to be made about vacation and holiday coverage and wages? How far in advance should they inform you about taking time off? How much time off and how often?
- Is the helper willing to do things the way your relative wants them done?
- Is the helper willing to be flexible and do extra tasks if the need arises?
- Are there cultural sensitivities or language abilities that should be addressed?

Make a list and discuss with the care helper what you expect them to do, how often and how you want tasks/activities to be performed. For instance, how many meals will be prepared each day, the time they will be served and the menu that will be followed. Or, consider identifying and discussing the specific cleaning duties to be completed, how often and what cleaning supplies might be used. Keep in mind the helper has been trained in basic health, home management and personal skills and may have valuable insight about your relative's care. Once you have agreed upon the specifics of the care to be provided, use this list to write a contract, so that both you and the care helper have a copy of what was agreed upon. Make sure you include what the helper should expect to happen if the terms of the contract are not met.

Many families choose to hire a care helper privately rather than through an agency. Be aware that as an employer you are required to complete certain payroll and tax documents including tax withholdings, FICA and other related taxes such as unemployment compensation. The care helper will also need to complete an I-9 form for immigration purposes. For a fee, independent accountants or local accounting firms will assist you and make sure you have completed all the required documents to protect you as the employer and the care helper as the employee.



### ❖ My relative has memory problems. Even though we discussed and agreed upon obtaining outside the family help, my relative has probably forgotten and might be resistant to accepting help. How do I introduce the care helper to my relative?

Most importantly, you should arrange to be present when a new care helper arrives at your relative's home. This provides an opportunity to observe and evaluate the situation. Have they received training in caring for persons with memory problems? Is the helper pleasant, professional, and sociable? Is your relative fearful, uneasy or in need of reassurance? Are they able to strike-up a conversation? Many times a new person or activity is scary and threatening for persons with memory disorders. Care helpers should be informed about

your relative's memory problem and their possible resistance to help prior to arriving at the home. Take advantage of this time to discuss possible approaches to be used for introducing your relative to the care helper so that they both may feel comfortable and at ease. For instance, introduce new home care workers as people who are there to help around the house, not to specifically assist the person who has memory problems. Also, you may want to provide information about your relative's likes and dislikes that may help the home care helper "break-the-ice" and promote social conversation.

### ❖ How should my relative and I communicate with the care helper to get what we want done but not make the person defensive or negative?

If you are unhappy with the care helper's performance, behavior or question their knowledge and/or skills, speak to the person immediately. It is very important that you learn some tips for communicating effectively, including:

- Make sure your message is clearly stated, such as: "When you do this, here's how it makes me feel."
- Don't use an accusing tone. Use phrases such as: "How do you think we can correct or change whatever is wrong?" "I would feel better if we tried it this way." "It makes me uncomfortable/upset/tense when you ----"
- Try to put the care helper at ease. Encourage the person to feel free to talk. Create an environment that supports good communication.
- Show the care helper that you are listening. Look and act interested in what they have to say.
- Don't jump to conclusions. Avoid making assumptions about what the care helper is going to say.
- Ask questions. Questions you ask should serve to guide the conversation.
- Be patient and flexible.

### ❖ What are some of the warning signs that may suggest potential problems of exploitation, abuse or neglect?

Some warning signs of potential problems include:

- Does the care helper prevent family or friends from visiting your relative? Is the care helper isolating your loved one from prying eyes?
- Does the care helper do all the talking? Do they make decisions for your relative?
- Has the care helper invited their friends or family into the home or used your relative's car without permission?
- Has your relative's personality changed since the care helper has been hired? Does your loved one appear afraid?
- Are there checks missing or made out to cash or to the care helper for more than the agreed amount? (Look for missing checks in the back of the checkbook or with the unused checkbooks.)

If you suspect your relative is being abused, neglected, and/or financially exploited by a care helper report your concerns to the care helper's employer. If you privately employ the care helper report the matter to Arizona Adult Protective Services (Central Intake Phone Number: 1-877-767-2385). However, if there is a clear indication of abuse, neglect and/or exploitation fire the care helper and immediately report the crime to Arizona Adult Protective Services (see above phone number) or the Pima County Elder Abuse Police Hotline (Ph: 790-7262), and the agency employing the care helper, if applicable.

# RESOURCES

- Pima Council on Aging,
  8467 E. Broadway Blvd.
  Tucson, Arizona 85710-4009
  Phone: (520) 790-7262
  www.pcoa.org
  - Pima Council on Aging publication:
    "Safety Tips for Hiring a Home Care Worker"
- Caregiver Consortium
  www.arizonacaregivers.org
- National Association for Home Care
  Phone: (202) 547-7424 or www.nahc.org
- National Council on the Aging
  www.benefitscheckup.com
- Family Caregiver Alliance
  Phone: (415) 434-3388 or www.caregiver.org
- Administration on Aging
  www.aoa.gov/caregivers/default.htm
- AARP LifeAnswers
  www.aarplifeanswers.com
- CareGuide
  www.careguide.com and click on: Care at Home
- AARP Andrus Foundation Publication,
  "Steps to Success: Decisions about Help at Home for Alzheimer's Caregivers"
  available on-line at
  www.andrus.org/caregiving or by mail from
  AARP Fulfillment EEO1526
  601 E St. N.W., Washington
  DC 20049 (request publication number D17623)

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

## CAREGIVER TIPS FOR MANAGING HOME CARE HELPERS

- Remove from the home, or lock up, all valuables (jewelry, artwork, cameras, etc.) as well as any cash, checkbooks and bank statements.
- Secure all mail. The care helper should not have access to important mail, such as: pension, social security and reimbursement checks or credit card solicitations. Credit card solicitations can be easily used by anyone to open an account in your relative's name. You may consider obtaining a post office box to make sure all mailed items are secure.
- Set-up a petty cash fund if the care helper will be shopping for your relative. Require the care helper to return receipts and any change from all purchases so that you can calculate the amount of petty cash remaining. NEVER GIVE A CARE HELPER A CREDIT CARD OR BLANK CHECK TO USE FOR SHOPPING.
- If the care helper will be driving your relative to medical appointments and other destinations consider doing the following, check your relative's insurance policy related to their coverage as a passenger in another person's vehicle. Make a copy of the care helper's current driver's license. You will need this information if there is an accident involving your relative's or care helper's car. Also, your insurance agent can use the license to check the care worker's driving record.
- Record on a calendar all scheduled or prearranged visits that will be made to your relative's home by friends, maintenance workers, gardeners and other local vendors. You may decide to initiate a rule that requires the care helper to contact you if there is a question about allowing strangers entry into your relative's home.
- Care helpers should not be allowed to accept gifts from your relative (with perhaps the exception of food items). This protects both your relative and the care helper if there is a question about the nature or circumstances surrounding the gift giving.
- If possible, make "spot checks" of your relative's home on the days that care helpers are scheduled to work. This will provide the opportunity to observe what is happening and whether or not it is appropriate.
- Don't forget about attending to the needs of your relative's pets. Outline the specific duties the care helper will be responsible for including daily routines and grooming.
- "Set boundaries" on the kinds of information (personal or business) that is appropriate to share and that which should not be shared with or by care helpers with other persons.
- Set rules about television viewing. The selection of television programs should be for the enjoyment of your relative not the care helper.
- Write down instructions or prepare a script describing how the care helper should answer, record messages and respond to telephone calls.
- Do not allow the care helper to begin a new exercise activity or program without first checking with your relative's physician.

Additional considerations include:

- Will care helpers be allowed to have their own relatives and friends visit?
- To what extent should care helpers be involved in socializing or participating in activities with your relative and his/her friends? Your relative may want private time with friends.
- If you hire a care helper who smokes cigarettes, it may be necessary to set limits on the amount of time taken to smoke, and the designated areas (inside and outside) where smoking will be allowed.

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# MANAGING CARE HELPERS IN THE HOME

*helping older relatives or friends prepare, supervise and plan for paid and/or volunteer help in the home*

## MANAGING CARE HELPERS

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## WHAT TO EXPECT

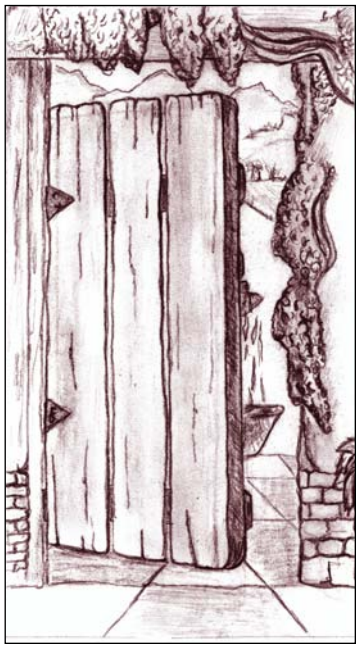
You should start with having realistic expectations of what the service can and cannot offer. Homemakers don't give baths and usually home health aides don't clean. You may have to train the care helpers to perform tasks the way you or your relative likes to have them done. Be aware that the same helper may not be available all the time depending on schedules, time-off and illness. Benefits to your relative may include companionship; different approaches to care leading to favorable results in health, functioning and behavior; and overall improved happiness and well-being. Benefits to you as the caregiver may include: respite/personal time; reduced stress; transportation for your relative to medical appointments and recreational activities; learning new caregiving skills; peace of mind; and a better relationship with your loved one.

## GATHERING INFORMATION

Begin by creating a **Personal Profile** of your relative. Write down information in the following areas:

- **Names** - the name your relative prefers to be called, names of family members, where they live and how they contribute to your relative's care.
- **Health** - medical conditions, treatments, medications, allergies, status of vision/hearing/ speech and aids used, and the location of advance directives, if applicable.
- **Eating/Drinking Preferences** - dietary restrictions, if any.
- **Daily Routines** - waking, sleeping, meal/snack times, exercise times and type of activities, best time of day, most difficult time of day.
- **Getting Around** - right/left handed, assistive devices used (canes, walkers, wheelchair), assistance needed both inside and outside of home, transportation used to medical/professional appointments.
- **Assistance/Supervision Needed with Daily Activities** - eating, dressing, grooming, bathing, etc.
- **Activities/Hobbies** – description of activity as well as time of day performed.
- **Emergency Contacts** - names and telephone numbers of: family members and friends, treating physicians, pharmacy(s) used, health insurance information, emergency medical department preference and poison control.

Make a copy of this information for all helpers involved in your relative's care. Care helpers must know what to expect.



## PROFILING HOME CARE HELPERS

What you are looking for in a home care helper is trustworthiness, reliability, dependability, skills, good-natured care and patience. You and your relative will need to observe and evaluate the helper(s). Consider asking yourself the following questions:

- Is the care helper compassionate, professional, calm and proud of their work?
- Is the care helper trained in first aid and other appropriate care techniques?
- If your relative has a Prehospital Medical Care Directive (orange card and page), does the care helper understand the terms of the directive and is willing to abide by them?
- Is the person willing to abide by household rules? (Smoking restrictions, TV or telephone use)
- What will happen if the helper has an emergency, is sick and/or unable to arrive at their scheduled time? Are there prearranged times when the care helper will not be available? Have they planned for problems with transportation, childcare, etc?

- What arrangements need to be made about vacation and holiday coverage and wages? How far in advance should they inform you about taking time off? How much time off and how often?
- Is the helper willing to be flexible and do extra tasks if the need arises?
- Are there cultural sensitivities or language abilities that should be addressed?

## BUSINESS ARRANGEMENTS

Make a list and discuss with the care helper what you expect them to do, how often and how you want tasks/activities to be performed. Once you have agreed upon the specifics of the care to be provided, use this list to write a contract, so that both you and the care helper have a copy of what was agreed upon. Make sure you include what the helper should expect to happen if the terms of the contract are not met.

Many families choose to hire a care helper privately rather than through an agency. Be aware that as an employer you are required to complete certain payroll and tax documents including tax withholdings, FICA and other related taxes such as unemployment compensation. The care helper will also need to complete an I-9 form for immigration purposes. For a fee, independent accountants or local accounting firms will assist you and make sure you have completed all the required documents to protect you as the employer and the care helper as the employee.

## INTRODUCING CARE HELPERS TO RELATIVES WITH MEMORY PROBLEMS

If possible, you should arrange to be present when a new care helper arrives at your relative's home. This provides an opportunity to observe and evaluate the situation. Have they received training in caring for persons with memory problems? Is the helper pleasant, professional, and sociable? Is your relative fearful, uneasy or in need of reassurance? Are they able to strike-up a conversation? Many times a new person or activity is scary and threatening for persons with memory disorders. Care helpers should be informed about your relative's memory problem and possible resistance to help prior to arriving at the home. Take advantage of this time to discuss possible approaches to be used for introducing your relative to the care helper so that both may feel comfortable and at ease. Also, you may want to provide information about your relative's likes and dislikes that may help the home care helper "break-the-ice" and promote social conversation.

## COMMUNICATING WITH CARE HELPERS

If you are unhappy with the care helper's performance, behavior or question their knowledge and/or skills, speak to the person immediately. It is very important that you learn some tips for communicating effectively, including:

- Make sure your message is clearly stated, such as: "When you do this, here's how it makes me feel."
- Don't use an accusing tone. Use phrases such as: "How do you think we can correct or change whatever is wrong?" "I would feel better if we tried it this way." "It makes me uncomfortable/upset/tense when you ----"
- Try to put the care helper at ease. Encourage the person to feel free to talk. Create an environment that supports good communication.
- Show the care helper that you are listening. Look and act interested in what they have to say.
- Don't jump to conclusions. Avoid making assumptions about what the care helper is going to say.
- Ask questions. Questions you ask should serve to guide the conversation.
- Be patient and flexible.

## WARNING SIGNS OF POTENTIAL PROBLEMS

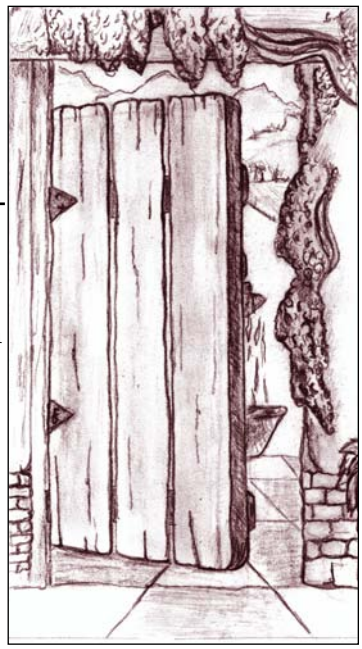
Some signs of potential problems include:

- Does the care helper prevent family or friends from visiting your relative? Is the care helper isolating your loved one from prying eyes?
- Does the care helper do all the talking? Do they make decisions for your relative?
- Has the care helper invited their friends or family into the home or used your relative's car without permission?
- Has your relative's personality changed since the care helper has been hired? Does your loved one appear afraid?
- Are there checks missing or made out to cash or to the care helper for more than the agreed amount? (Look for missing checks in the back of the checkbook or with the unused checkbooks.)

If you suspect your relative is being abused, neglected, and/or financially exploited by a care helper report your concerns to the care helper's employer. If you privately employ the care helper report the matter to Arizona Adult Protective Services (Central Intake Phone Number: 1-877-767-2385). However, if there is a clear indication of abuse, neglect and/or exploitation fire the care helper and immediately report the crime to Arizona Adult Protective Services (see above phone number) or the Pima County Elder Abuse Police Hotline (Ph: 790-7262), and the agency employing the care helper, if applicable.

# MANEJANDO CUIDADORES EN EL HOGAR

*Ayudando a parientes y amigos envejecidos preparar, supervisar y planear para cuídadores voluntarios o de paga en el hogar*



## PREGUNTAS QUE SURGEN PREGUNTAR FRECUENTEMENTE SOBRE MANEJAR CUIDADORES DE AYUDA

Ser cuídador familiar no quiere decir que uno tiene que hacer todo si mismo. Se trata de asegurar que las necesidades del pariente sean logradas. En este papel, podra llegar el tiempo que usted y su pariente decidan comenzar usar ayuda fuera de lo que la familia y amigos puedan rendir. Esta decisión debe ser realizada con su pariente si es posible, basandose en las selecciones informativas entre opciones disponibles de cuídado en casa, buen juicio y hayar un servicio que esté en acuerdo con la situación de cuídado familiar. El seguiente paso, despues de contratar un cuídador de paga o arreglar la ayuda de un voluntario, es prepararse uno mismo y su pariente para compartir su hogar y supervisar el cuídado diario que se va rendir. La seguiente información le ayudará a guíarla en manejar la ayuda de un cuídador en casa con éxito.

### ❖ ¿Qué debemos mi pariente y yo esperar en ganar cuando acceptemos la ayuda de paga o voluntariamente y lleguemos a dejar a alguíen entrar en nuestro hogar?

Deben comenzar con tener expectaciones realisticas de lo que el servicio puede y no puede ofrecer. Las amas de casa no dan baños y por lo costumbre los asistentes de salud no hacen la limpieza. Quizás usted tendra que enseñar al cuídador hacer ciertos quehaceres de la manera que usted y su pariente les gusta que se hagan. Tenga en cuenta que no todo el tiempo podrá tener la misma persona como cuídador según el horario, tiempo libre y enfermedad. Los beneficios para su pariente incluyen la compañía; diferentes modos de cuídado que puedan dirigir a mejoramiento de salud, funcionamiento y comportamiento; y sobretodo mejoramiento de bien estar y felicidad. Los beneficios para usted como cuídador podrán incluír: tiempo para descansar y tiempo personal; reducción de tensión; transportación para su pariente a todas las citas médicas y actividades de recreación; apprender técnicas de cuídar nuevas; tranquilidad de mente; y posiblemente el mejoramiento de la relación con su ser querido.

### ❖ ¿Qúe tipo de información debo de reunir que pueda ayudar al cuídador entender las necesidades, los gustos y las aversiones de mi pariente?

Comienze con crear un perfil personal de su pariente. Apunte información sobre lo seguiente:

- **Nombre** – el nombre que su pariente prefiere que se le llame, nombres de los miembros de la familia, donde viven y como contribuyen al cuídado de su pariente.
- **Salud** – condiciones médicas, tratamientos, medicamentos, alergias, estado de vista/oído/hablar y uso de aparatos de ayuda, etc. y el lugar donde se encuentran las directivas avanzadas, si es aplicable.
- **Preferencia de comida y bebidas** – restricciones de dieta, si hay.
- **Rutinas diarias** – tiempo de despertar, dormir y merendar/botanear, hacer ejercicios y tipo de actividad, el mejor tiempo del día y el más difícil tiempo del día.
- **Movimiento** – mano derecha o surda, mecanismos asistivos (bastón, andadera, silla de ruedas), asistencia necesaria dentro y fuera del hogar, transportación que se usa para asistir a citas médicas y profesionales.
- **Asistencia/Supervisión necesaria para conducir actividades diarias** – comer, vestir, peinar, bañar, etc.
- **Actividades/Actividades de Distracción** – una descripción de la actividad y también la hora del día en que se hace.

- **Contactos de Emergencia** – nombres y números de teléfono de: miembros de familia y amigos, médicos atendiendo, farmacia(s) que ocupan, información de seguro de salud, preferencia de departamento médico emergente y control de veneno.

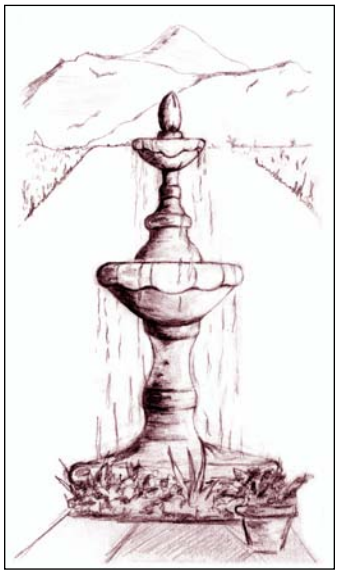
Haga una copia de está información para todo los que ayudan a cuídar a su pariente. Los cuídadores deben saber que esperar.

## ❖ ¿Qúe preguntas debo preguntar para asegurar que el cuídador entienda lo que mi pariente y yo necesitamos?

Lo que usted está buscando en el cuídado en el hogar es una persona servicial, digno de confianza, fiable, con buenas técnicas, bondadoso y paciente. Usted y su pariente necesitan observar y evaluar al ayudante. Quizá quiera preguntarse lo seguiente para ayudarle:

- ¿Es el ayudante compasivo, profesional, calmado, y orgulloso de su trabajo?
- ¿Está el ayudante bien cualificado en los primeros auxilios y otras técnicas de cuídado apropiadas?
- Si su pariente tiene directivas de cuídado médico antes de hospitalizar (carta y/o pagina naranjada), ¿entiende el cuídador los términos de las directivas y está dispuesto a seguirlos?
- ¿Qúe puede hacer el cuídador para ayudarnos ahora?
- ¿Está el cuídador dispuesto seguir los reglamentos del hogar? (Restricción de fumar, y/o el uso de televisión o teléfono).
- ¿Qúe arreglos hay si el ayudante tiene una emergencia, se enferma y/o no puede llegar al tiempo puesto? ¿Hay tiempos organizados antemano que el cuídador no está disponible? ¿Ha hecho el cuídador arreglos para problemas con transportación, cuídado de niño, etc.?
- ¿Qúe clase de arreglos se deben hacer para vacaciones y días festivos y sueldos? ¿Qúe tanto tiempo en antemano quiere usted tener para avisarle de tiempo libre? ¿Qúe tanto tiempo pueden tomar libre y con qúe tanta frequencia?
- ¿Está el ayudante dispuesto hacer las cosas como su pariente lo desea que se hagan?
- ¿Está el ayudante dispuesto ser flexible y hacer tareas o mandados extras si es necesario?
- ¿Hay ciertas comprensiones culturales o capacidades de idioma que se deben discutir?

Haga una lista y converse con su ayudante de lo que usted espera que el/ella haga, que tan frequentemente se debe hacer y como usted quiere que se haga. Por ejemplo, qué tantas comidas se deben preparar al día, el tiempo que se deben servir y el menú que se debe seguir. O, considere identificar y conversar las obligaciones detalladamente de la limpieza que se debe hacer, con qué tanta frequencia se deben hacer, y qué clase de materiales de limpieza se pueden usar. Tenga en cuenta que el cuídador está entrenado en la salud basica, mantenimiento del hogar, y técnicas personales y puede tener capacidad perspicaz valorable del cuídado de su pariente. Cuando esté de acuerdo con los detalles de cuídado que se tienen que rendir, use esta lista para escribir un contrato para que usted y el cuídador tengan una copia propia de lo que estan de acuerdo. Asegure de incluír qué es lo que el cuídador debe esperar que se haga si acaso los terminos del contrato no se llevan acabo.



Muchas familias prefieren emplear un cuídador en privado en lugar de usar una agencia. Mantenga en cuenta qué como un patron, se deben llenar ciertos documentos de empleo y impuestos incluyendo impuestos de retención, FICA, y otros impuestos relacionados como la compensación de desempleo. El cuídador también debe llenar la forma I-9 para el proposito de imigración. Por un cierto precio, un contador independiente o organización de contabilidad puede asistirle y asegurar que usted tenga todos los documentos apropiados para protegerse como patron y proteger el cuídador como empleado.

❖ **Mi pariente tiene problemas con su memoria. Aunque hablamos y quedamos de acuerdo en conseguir ayuda fuera de la familia, mi pariente probablemente ha olvidado y quizá se oponga en aceptar la ayuda. ¿Cómo le presento a mi pariente el cuídador?**

Principalmente, debe usted hacer arreglos para estar presente cuando el cuídador nuevo llegue a la casa de su pariente. Esto presenta una oportunidad para observar y evaluar la situación. ¿Há recibido el cuídador entrenamiento in cuídar a personas con problemas de memoria? ¿Es el cuídador agradable, profesional y sociable? ¿Está su pariente temeroso, intranquilo o en necesidad de consuelo? ¿Estan aptos de comenzar una conversación? Muchas veces una persona con problemas de memoria se sienten amenazados o asustados por personas o actividades nuevas. Se le debe avisar al cuídador antes de llegar a la casa de su pariente de los problemas de memoria que tiene su pariente y posiblemente la resistencia de ayuda que puede haber. Tome esta oportunidad de discutir diferentes maneras que se pueden usar para introducir su pariente al cuídador para hacerlos sentir agustos y confortables. Por ejemplo, presente al cuídador como una persona que estará en el hogar para ayudar en el hogar y no para asistir a la persona con problemas de memoria especificamente. También, usted puede informar al cuídador de los gustos y aversiones que su pariente tiene para ayudar al cuídador con la conversación inicial y promover una conversación social.

❖ **¿Cómo debemos mi pariente y yo comunicar con el cuídador para que haga lo que queremos y no hacerlo sentir defensivo o negativo?**

Si ustedes estan insatisfechos con el funcionamiento, comportamiento o sospechan del conocimiento y/o habilidad del cuídador, hable con el cuídador inmediatamente. Es muy importante que ustedes aprendan las varias maneras de comunicar eficazmente, que incluyen lo seguiente:

- Esté seguro que su mensaje sea indicado claramente tal como: "Cuando usted hace esto, asi me hace sentir."
- No use un tono acusador. Use frases tal como: "¿Cómo piensa usted que podemos corregir o cambiar lo que está mal?" "Me sintiera mejor si lo intentaramos de esta manera." "Me siento incomfortable/alterado/tenso cuando usted _____"
- Trate de hacer el cuídador sentirse cómodo. Anime al cuídador para que pueda hablar libremente. Forme un ambiente que apoye una comunicación buena.
- Enseñele al cuídador que está escuchando. Tenga una aspecto y manera de interes en lo que el cuídador tenga que decir.
- No saque a la ligera una conclusión. Trate de prevenir suposiciones de lo que el cuídador esté por decir.
- Haga preguntas. Las preguntas que usted haga deben servir para guiar la conversación.
- Sea paciente y flexible.

❖ **¿Qúe son las señas de advertencia que puedan sugerir los problemas potentes de explotación, abuso o negligencia?**

Unas señas de advertencia que indican que probablemente hay problemas incluyen:

- ¿Ha prevenido el cuídador a la familia o amistades de visitar al pariente? ¿Ha aislado el cuídador a su ser querido de sus ojos entrometidos?
- ¿Solamente el cuídador habla? ¿Hace el cuídador las decisiones de su pariente?
- ¿Ha invitado el cuídador as sus amistades o familia a la casa de su pariente o ha usado el auto de su pariente sin permiso?

- ¿Ha cambiado la personalidad de su pariente desde que el cuídador fue empleado? ¿Aparece su pariente temeroso?
- ¿Estan cheques extraviados o hechos "Al Portador" o en efectivo o al nombre del cuídador por más de la cantidad que estaba de acuerdo? (Busque cheques extraviados atras de la chequera o en las chequeras que no se estan usando.)

Si sospecha que su pariente lo estan abusando, está desatendido y/o está económicamente explotado por el cuídador o ayudante, puede usted reportar sus preocupaciones al patrón del cuídador. Si usted emplea al cuídador privadamente entonces puede reportar el asunto a Los Servicios de Protección para Adultos de Arizona ("Arizona Adult Protective Services") (Teléfono de servicios central: 1-877-767-2385). Sin embargo, si hay indicaciones claras de abuso, negligencia, y/o explotación despida al cuídador y inmediatamente reporte el crimen a Los Servicios de Protección para Adultos de Arizona ("Arizona Adult Protective Services") ( a el teléfono indicado anteriormente) o al "Pima County Elder Abuse Police Hotline" (teléfono 790-7262) y a la agencia que emplea al cuídador, si es aplicable.

## RECURSOS

- El Concilio de Envejecimiento de Pima (Pima Council on Aging), 8467 E. Broadway Blvd., Tucson, Arizona 85710-4009; Teléfono: (520) 790-7262; www.pcoa.org
- Publicación por El Concilio de Envejecimiento de Pima (Pima Council on Aging): "Consejos de Seguridad Cuando Se Emplea Un Trabajador de Cuídado en Casa" ("Safety Tips for Hiring A Home Care Worker")
- El Consorcio de Cuídadores (Caregiver Consortium); www.arizonacaregivers.org
- La Asociación Nacional De Cuídado En Casa (National Association for Home Care), Teléfono (202)547-7424 o www.nahc.org
- El Concilio Nacional de Envejecimiento (National Council on the Aging), www.benefitscheckup.com
- La Alianza de Cuídadores de Familia (Family Caregiver Alliance); Teléfono: (415)434-3388 o www.caregiver.org
- La Administración de Envejecimiento (Administration on Aging); www.aoa.gov/caregivers/default.htm
- Respuestas De La Vida por la Asociación de Personas Americanas Jubiladas (AARP Life Answers); www.aarplifeanswers.com
- Guía de Cuídado (CareGuide); www.careguide.com y toque: "Care at Home"
- La Publicación por la Fundación AARP Andrus (AARP Andrus Foundation Publication); "Pasos al Exito: Decisiones de Ayuda en Casa para los Cuídadores Que Cuídan Personas con Alzemia" ("Steps to Success: Decisions about Help at Home for Alzheimer's Caregivers"); disponible electrónicamente en el "Internet" a www.andrus.org/caregiving o por correspondencia de AARP Fulfillment EE01526, 601 E St N.W., Washington, DC 20049 (solicite la publicación número D17623)

*Preparado para El Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

## CONSEJOS PARA QUE EL CUIDADOR PUEDA SUPERVISAR EL AYUDANTE DE CUIDADO EN CASA

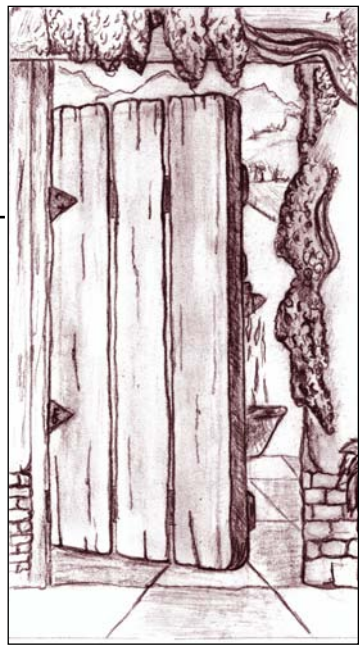
- Translade del hogar o mantenga bajo candado, todas las cosas con mucho valor asi como joyas, arte, cámaras, dinero, chequeras y detalles de cuentas bancarias.
- Asegure toda la correspondencia. El ayudante de cuídado no debe tener acceso a ninguna correspondencia importante asi como: fondo de pensión, cheques de seguro social y reembolsos o solicitudes de tarjetas de crédito. Las solicitudes de tarjetas de crédito pueden ser facilmente usadas por cualquiera persona para abrir una cuenta bajo el nombre de su pariente. Puede usted considerar conseguir un apartado postal para asegurar que todas clases de correspondencia no lleguen a las manos de alguien con mala intención.
- Consiga un fondo aparte para gastos menores si el ayudante de cuídado estará encargado de hacer las compras por su pariente. Haga que el ayudante le entregue todos los recibos y cambio en efectivo de todas las compras para que usted pueda calcular la cantidad que debe de quedar en éste fondo. NUNCA LE DE DINERO EN EFECTIVO O CHEQUE EN BLANCO AL AYUDANTE DE CUIDADO PARA LAS COMPRAS.
- Si el ayudante de cuídado estará manejando para llevar a su pariente a las citas del médico y a otros sitios, entonces considere lo seguiente: revise la póliza de seguro de automóvil de su pariente para saber si su pariente está asegurado por mientras es pasajero en el vehiculo de otra persona. Haga una copia de la licencia de conducir del ayudante de cuídado que esté al corriente. Usted necesitara esta información si acaso hay un accidente en el auto de su pariente o en el auto del ayudante de cuídado. También, su agente de seguro puede usar la licensia para revisar los archivos de conducimiento de auto del ayudante de cuídado.
- Anote en un calendario todas las citas y visitas pre-arregladas que se van hacer al hogar de su pariente por amistades, trabajadores de mantenimiento, jardineros, y otros vendedores locales. Pueda ser que usted quiera iniciar un reglamento que requiera que el cuídador le llame a usted si hay duda en dejar estraños entrar en la casa de su pariente.
- Ayudantes de cuídado no deben ser permitidos de recibir regalos de su pariente (con la excepción de comida). Esto protégé a ambos, a su pariente y al ayudante de cuídado, si acaso hay una pregunta sobre la naturaleza o las circumstancias alrededor del regalo.
- Si es posible, revise "aquí y allá" la casa de su pariente en los días que el ayudante de cuídado está citado a trabajar. Esto dara una oportunidad de observar que los que esta pasando y si es o no es apropiado.
- No se olvide atender las necesidades de los animales de su pariente. Detalle los deberes especificamente del ayudante de cuídado que estará responsable incluyendo las rutinas diarias y las preparaciones personales.
- Establezca limitaciones en la clase de información (personal y de negocio) que sea apropiado en compartir y lo que no se debe compartir con o por los ayudantes de cuídado con otras personas.
- Establezca reglas de ver televisión. Los programas en televisión deben ser seleccionados para que su pariente disfrute y a su gusto y no solo para el ayudante de cuídado.
- Escriba las instrucciones o prepare una escritura detallando como el ayudante de cuídado debe contestar llamadas telefonicas, tomar mensajes y responder a las llamadas.
- No permita que el ayudante de cuídado comienze una actividad de ejercicio nueva o programa antes de consultar con el médico de su pariente.

Otras consideraciones incluyen::

- ¿Podrá el ayudante de cuídado tener permiso de dejar sus propios parientes o amistades visitarlo?
- ¿Hasta cual punto podrá el ayudante de cuídado socializar y/o participar en las actividades con su pariente y sus amistades? Su pariente podrá querer el tiempo con sus amistades en privado.
- Si contrata un ayudante de cuídado que fuma cigarros, tal vez sea necesario de establecer limites de la cantidad de tiempo que puede tomar y designar las areas (dentro y fuera) donde se puede fumar.

# LONG DISTANCE CAREGIVING

*helping long distance caregivers to prepare for the current and future care of older relatives*



## FREQUENTLY ASKED QUESTIONS ABOUT LONG DISTANCE CAREGIVING

The act of caregiving has been going on for centuries. What has changed is that many people are living away from their families. Caregiving is considered long distance if it requires travel of at least one hour to reach your loved one. If you are a long distance caregiver, you are not alone. Nearly 7 million Americans manage care for an older relative or friend who lives at a distance. The following information offers suggestions on how to evaluate, plan and organize your resources and time to maximize your ability to provide support from a distance.

❖ **Shortly after my father's medical diagnosis, I went home to visit. He reassured me he could take care of himself, but I am not convinced. How can I help?**

During your visits, assess your loved one's situation. A person may be willing to give up a great deal in order to live independently in their own home. Older persons should maintain control over their own decision making as long as there is no threat to their physical and mental well-being. Talk with your relative about your concerns. Be careful not to anger or make your loved one defensive; rather involve your relative in recognizing and solving the problem(s) at hand. Remember your relative's perception of the situation may be very different from yours. You may think your loved one is no longer capable of performing certain tasks, when, in fact, all that is needed is more time for your relative to complete the task. Identify the type of help your relative thinks is needed and would be willing to accept. Remember to be sensitive and caring and treat your loved one with respect. Ask yourself, how would I feel if my relative was getting involved in my personal life?

❖ **What is involved in creating a plan of care that provides the help and support my loved one needs and is willing to accept?**

Together with your relative create a plan of care that may include both informal and formal supports.

**Informal Support:** Other family members may already be (or want to be) involved in the care of your relative. Meet with your family members to decide how to work together effectively as a team. Also, identify friends, neighbors and members of faith groups, associations and societies to which your relative may belong and who may be available to provide assistance. Try not to overwhelm people, but be sure to openly discuss what types of help they may be willing and able to perform. Be as direct as possible and make sure all understand the situation and share your concerns. Introduce yourself to everyone who will be helping your relative, if you do not already know them. Keep a list of their phone numbers and addresses. Let them know they can call you collect anytime day or night if they are worried about your loved one. Develop ways to show appreciation and recognition of the help they are giving (such as, friendly phone calls, thank you notes, cards etc.).

**Formal Support:** Formal support is provided by public and private agencies that offer professional health and social services for the elderly. Educate yourself about resources and services that are available in your relative's community. Contact the Area Agency on Aging serving your relative's community to determine which local agencies provide the type of help you

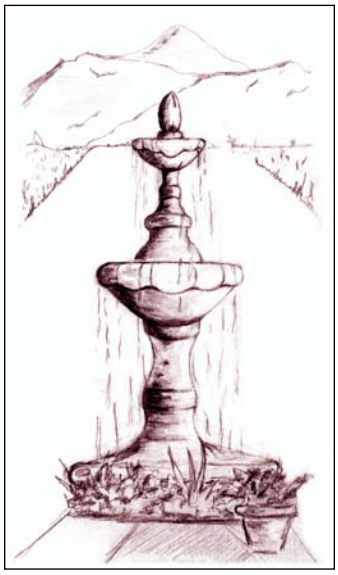
are looking for. Pima Council on Aging (PCOA) is the Area Agency on Aging serving older adults residing in Pima County. PCOA can help you identify local resources and services as well as connect you with the Area Agencies on Aging serving other geographic locations throughout the United States. Another resource is the Eldercare Locator service (Ph: 1-800-677-1116; Mon.-Fri.; 9am-8pm Eastern Time), a nationwide program that will identify the Area Agency on Aging and other service providers located in your relative's community. Communities vary widely in the types of services they offer the elderly. Some considerations include: Are there publicly funded professional services available? If so, are there waiting lists for the services your relative needs? Are there co-payments for these services? What services are privately available? What are the associated costs? How are services monitored to determine the quality of care being provided?

### ❖ What do I need to do for myself in order to prepare for what may lie ahead as a long distance caregiver?

As a long distance caregiver, you must come to terms with what you can and cannot do. You will need to determine how much assistance you are willing and able to provide. You should follow a course that fits your personal strengths, resources and life style. Make the most of visits with your relative. Each visit should be balanced between accomplishing business matters, time to enjoy your loved one's company, as well as observing and monitoring the overall situation. Plan in advance what you would like to undertake during the visit, such as: gathering medical, financial and legal information; visits to local social service agencies, residential housing or assisted living facilities; entertaining and socializing with your relative, family and friends; reminiscing; having heart-to-heart conversations with your relative, if appropriate, etc. Since long distance caregiving means regular telephone calls, look into saving plans and discounts on long distance telephone service. You will need to be prepared for emergencies and if necessary be ready to travel at a moments notice. You may want to consider: keeping your car in good repair; making sure you have a valid driver's license and current auto insurance; collecting current bus, train and airline schedules; and keeping your travel documents current. Put aside money in a special fund to pay for such trips/visits. Assess your caregiving responsibilities considering your other obligations, such as your health, family and work. You may need to plan ahead at work to have Family Leave or personal days available in case an unexpected visit to your relative is needed.

### ❖ What do I need to discuss with my employer about my caregiving responsibilities?

You and your employer may want to arrange a schedule for you to take time off every few months to visit your relative. It is better not to wait for a crisis situation but to discuss your plans with your employer in advance. You may have the right to receive Family Medical Leave. The Family Medical Leave Act of 1993, grants employees of firms with more than 50 employees the right to take up to 12 weeks leave of absence without pay in a 12-month period to take care of a child, family member or yourself with a serious illness and still be guaranteed a job and continuation of benefits. You are able to take this leave in portions of time, i.e., a few hours a week, or a day a month, or a week every few months. Check with your employer to see: 1) if your vacation/sick time can be applied to the time you take off, and 2) if you must be employed at your current job for a certain length of time before you are eligible for Family Medical Leave.



### ❖ Sometimes I am not sure if my concerns about my loved one are significant problems or not. How do I know when the situation is serious enough to require immediate action?

If you are dealing with an obvious emergency situation your foremost concern should be to get to your loved one quickly. Crisis situations that demand your immediate attention include: a serious accident or medical

condition, or if no one has been able to contact your relative. If the situation is not an emergency, you may want to ask yourself the following questions to help determine whether or not a personal visit is necessary:

- What do your relative's local support persons (both informal and formal) think about the situation? What does your relative's primary physician recommend?
- What is your relative's style? For example, the tendency to underestimate or exaggerate the seriousness of a situation.
- What is your style? How much anxiety/stress can you tolerate before deciding to go?

More practical considerations include:

- Can you afford the trip right now?
- Is work a consideration? Do you have accrued vacation and/or sick time? Are you eligible for Family Medical Leave?
- What arrangements have you made, or do you need to make, to meet your responsibilities to your spouse, children and other household members?

❖ **I've been thinking about either relocating to be closer to my relative, having my relative relocate to a location within my community, or perhaps having my relative live with me and my family. What should I consider before making my final decision?**

Talk with your relative about these alternatives in advance, before a crisis situation occurs. Factors to consider before moving or relocating an older relative include:

- Does your relative want to live in your city or within your household? What are your relative's needs for independence and familiarity with friends and community? It may be difficult to leave old friends and make new friends in a different city.
- Would your relative be willing to relocate to assisted living or some other supportive living environment within your community? Many times older persons do not want to live in the same household as their adult children.
- What housing options are available for your relative in your city? How will housing be paid for?
- What publicly funded community resources are available and accessible to help your relative, if needed? States differ in what services are available as well as eligibility criteria for participation in services and programs.
- Be realistic about what it would take to live again with your parent in their house or in yours. Would this be the best situation for both of you? Consider having your relative for a visit in order to evaluate whether living together in the same household is a possible alternative.
- What is your emotional and physical capability to deal with your relative's care needs?
- What is your past relationship with your relative? Are there any unresolved conflicts with your relative? If so, consider if resolution is possible before moving your relative.
- What safety, privacy and space modifications would have to be made to your home to accommodate your relative's needs?
- What are your needs, your relative's needs and the needs of other household members? What lifestyle differences exist?
- How long do you expect the arrangement to last?

## RESOURCES

- Pima Council on Aging
8467 E. Broadway Blvd.,
- Tucson, Arizona 85710-4009
Phone: (520) 790-7262
www.pcoa.org
- Caregiver Consortium
www.arizonacaregivers.org
- CareGuide
www.careguide.com and click on: Care for Caregivers
- Heritage Planning Series
www.pebco.org
- Heath, Angela. "Long Distance Caregiving: A Survival Guide for Far Away Caregivers." American Source Books, 1993, 121 pp. $9.95. Call 303-980-0580 to order.
- Eldercare Locator
www.eldercare.gov/elderpage/locator.html
- Building Better Health
www.buildingbetterhealth.com/topic/caregiveld
- How to Care
www.howtocare.com/caregiving2.htm
- National Family Caregiver Association
10400 Connecticut Ave. Suite 500
Kensington, MD 20895
Ph: 1-800-896-3650
email: infor@nfcacares.org
web: www.nfcacares.org/FAQ's.html
- AARP LifeAnswers
www.aarp.org/confacts/caregiver/longdistance.html
- PDIA Caregiver Bibliography
www.soros.org/death/agingparents.html

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

## TIPS FOR LONG DISTANCE CAREGIVERS

- Visit as often as possible and make the most of your visits. Be observant when you are visiting. Do you notice anything new or unusual in your relative's health and functional status?
- Discuss your concerns with family members, call a family meeting if possible.
- Allow yourself time to search the Internet and other information sources about medical concerns, local resources and services and caregiving information.
- Establish a routine. Stay in regular contact, either by telephone, e-mail or letters. Send news-like letters about events in your life and at the same time make friendly reminders about preparations or things they may have forgotten or postponed doing. Your emotional support is important and your advice in helping them make decisions is a form of caregiving. Try to talk to both of your parents at the same time by having one get on the extension phone.
- Set-up a list of telephone numbers, e-mail and mailing addresses of relatives and friends to keep them informed.
- Take notes. Write down highpoints, dates and times of conversations with health professionals and personal helpers.
- Create a log or a journal to keep track of important information, such as: notes and observations on your relative's health status, names and contact information for helpers, travel information, legal, financial and insurance information, etc.
- Contact the Area Agency on Aging serving your relative's community. Also, obtain a copy of the Yellow Pages for your relative's city/community. It will help you locate local services and agencies in your relative's community while you are at home. Ordering a directory for mail delivery can be very expensive. Instead pick-up one free at your relative's local phone service location. Also, you can access the Yellow Pages and White Pages on-line at: www.Smartpages.com
- Assess housing features that may need modification to support safe ambulation and other activities.
- Learn about helpful products and assistive devices, such as a personal emergency response system (a device that summons emergency assistance services when the wearer presses a button).
- Be aware of hidden demands and expectations placed on caregivers by society and culture that may contribute to feelings of guilt and isolation.
- Don't feel you have to stick with one solution if it isn't working out. Be flexible.
- Trust your feelings and intuition. Sometimes the ones we love hold back information not wanting to upset us.
- Learn to give graciously so that parents don't sense resentment or hostility.

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# LONG DISTANCE CAREGIVING

*helping older relatives or friends plan and make informed decisions about their future care*

The act of caregiving has been going on for centuries. What has changed is that many people are living away from their families. If you are a long distance caregiver, you are not alone. Nearly 7 million Americans manage care for an older relative or friend who lives at a distance.

## TALKING ABOUT YOUR CONCERNS

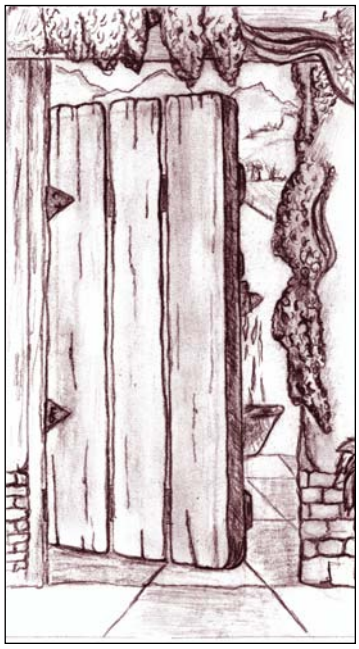
A person may be willing to give up a great deal in order to live independently in their own home. Older persons should maintain control over their own decision making as long as there is no threat to their physical and mental well-being. Talk with your relative about your concerns. Be careful not to anger or make your loved one defensive; rather involve your relative in recognizing and solving the problem(s) at hand. Remember your relative's perception of the situation may be very different from yours. You may think your loved one is no longer capable of performing certain tasks, when, in fact, all that is needed is more time for your relative to complete the task. Identify the type of help your relative thinks is needed and would be willing to accept. Remember to be sensitive and caring and treat your loved one with respect. Ask yourself, how would I feel if my relative was getting involved in my personal life?

## CREATING A PLAN OF CARE

Together with your relative create a plan of care that may include both informal and formal supports.

**Informal Support:** Other family members may already be (or want to be) involved in the care of your relative. Meet with your family members to decide how to work together effectively as a team. Also, identify friends, neighbors and members of groups to which your relative may belong and who may be available to provide assistance. Try not to overwhelm people, but be sure to openly discuss what types of help they may be willing and able to perform. Keep a list of their phone numbers and addresses. Let them know they can call you collect if they are worried about your loved one. Develop ways to show appreciation and recognition of the help they are giving.

**Formal Support:** Formal support is provided by public and private agencies that offer professional health and social services for the elderly. Educate yourself about resources and services that are available in your relative's community by contacting the local Area Agency on Aging. Pima Council on Aging (PCOA) is the Area Agency on Aging serving older adults residing in Pima County. PCOA can help you identify local resources and services as well as connect you with the Area Agencies on Aging serving other geographic locations throughout the United States. Another resource is the Eldercare Locator service (Ph: 1-800-677-1116; Mon.-Fri.; 9am-8pm Eastern Time), a nationwide program that will identify the Area Agency on Aging and other service providers located in your relative's community. Communities vary widely in the types of services they offer the elderly. Some considerations include: Are there publicly funded professional services available? If so, are there waiting lists for the services your relative needs? Are there co-payments for these services? What services are privately available? How are services monitored to determine the quality of care being provided?



## PREPARING IN ADVANCE

You will need to determine how much assistance you are willing and able to provide. You should follow a course that fits your personal strengths, resources and life style. Make the most of visits with your relative. Each visit should be balanced between accomplishing business matters, time to enjoy your loved one's company, as well as observing and monitoring the overall situation. Since long distance caregiving means regular telephone calls, look into saving plans and discounts on long distance telephone service. You will need to be prepared for emergencies and if necessary be ready to travel at a moments notice. You may want to consider: keeping your car in good repair; making sure you have a valid driver's license and current auto insurance; collecting current bus, train and airline schedules; and keeping your travel documents current. Put aside money in a special fund to pay for such trips/visits. Assess your caregiving responsibilities considering your other obligations, such as your health, family and work.

## BALANCING WORK AND CAREGIVING

You and your employer may want to arrange a schedule for you to take time off every few months to visit your relative. It is better not to wait for a crisis situation but to discuss your plans with your employer in advance. You may have the right to receive Family Medical Leave. The Family Medical Leave Act of 1993, grants employees of firms with more than 50 employees the right to take up to 12 weeks leave of absence without pay in a 12-month period to take care of a child, family member or yourself with a serious illness and still be guaranteed a job and continuation of benefits. You are able to take this leave in portions of time, i.e., a few hours a week, or a day a month, or a week every few months. Check with your employer to see: 1) if your vacation/sick time can be applied to the time you take off, and 2) if you must be employed at your current job for a certain length of time before you are eligible for Family Medical Leave.

## RECOGNIZING CRISIS SITUATIONS

In an obvious emergency situation you should get to your loved one quickly. Crisis situations that demand your immediate attention include: a serious accident or medical condition, or if no one has been able to contact your relative. If the situation is not an emergency, you may want to ask yourself the following questions to help determine whether or not a personal visit is necessary:

- What do your relative's local support persons (both informal and formal) think about the situation? What does your relative's primary physician recommend?
- What is your relative's style? For example, the tendency to underestimate or exaggerate the seriousness of a situation.
- What is your style? How much anxiety/stress can you tolerate before deciding to go?

More practical considerations include:

- Can you afford the trip right now?
- Is work a consideration? Do you have accrued vacation and/or sick time? Are you eligible for Family Medical Leave?
- What arrangements have you made, or do you need to make, to meet your responsibilities to your spouse, children and other household members?

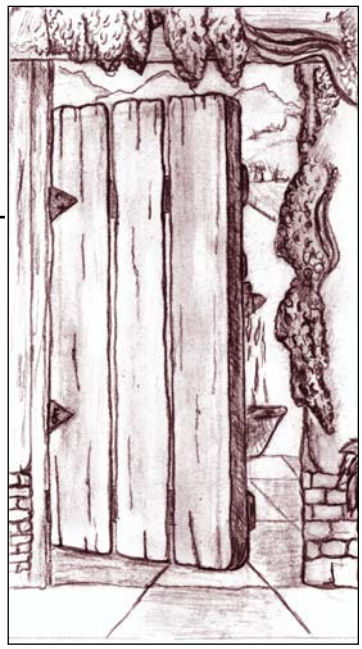
## RELOCATION AS AN OPTION

At some point, you may consider moving to be closer to your relative, having your relative relocate to a location within your community, or perhaps having your relative live with you. Talk with your relative about these alternatives in advance, before a crisis situation occurs. Factors to think about include:

- Does your relative want to live in your city or within your household? What are your relative's needs for independence and familiarity with friends and community?
- Would your relative be willing to relocate to assisted living or some other supportive living environment within your community?
- What housing options are available for your relative in your city? How will housing be paid for?
- What publicly funded community resources are available and accessible to help your relative, if needed? States differ in what services are available as well as eligibility criteria for participation in services and programs.
- Be realistic about what it would take to live again with your parent. Would this be the best situation for both of you? Consider having your relative for a visit in order to evaluate whether living together is a possible alternative.
- What is your emotional and physical capability to deal with your relative's care needs?
- What is your past relationship with your relative? Are there any unresolved conflicts with your relative? If so, consider if resolution is possible before moving your relative.
- What safety, privacy and space modifications would have to be made to your home to accommodate your relative's needs?
- What are your needs, your relative's needs and the needs of other household members? What lifestyle differences exist?
- How long do you expect the arrangement to last?

# CUIDADO A LARGA DISTANCIA

*Ayudando a cuídadores a larga distancia preparar para el cuídado presente y futuro de su pariente envejecido*



## PREGUNTAS QUE SURGEN PREGUNTAR FRECUENTEMENTE SOBRE EL CUIDADO A LARGA DISTANCIA

El acto del cuídador ha estado en existencia por siglos. Lo qué ha cambiado es que hoy mucha gente se encuentra viviendo lejos de sus familias. El cuídado se considera de larga distancia cuando se requiere viajar por lo menos una hora para llegar al lado de su ser querido. Si usted es cuídador de larga distancia, no está solo. Hay cerca de 7 millones de Americanos que mantienen el cuídado de un pariente o amigo envejecido que viven lejos. La seguiente información ofrece consejos de como evaluar, planear y organizar sus recursos y tiempo para poder maximar su habilidad de rendir apoyo de lejos.

❖ **Un corto tiempo despues que a mi padre se le dio el diagnosis médico, lo fuí a visitar. El me aseguro que se podía cuídar solo pero no estoy convencida. ¿Cómo puedo ayudar?**

Durante su visita, evalue la situación de su ser querido. Una persona puede perder voluntariamente mucho para poder seguir viviendo en su hogar independientemente. Personas envejecidas deben mantener control de la habilidad de hacer sus propias decisiones por mientras que no exista ninguna amenaza a su bienestar físico y mental. Hable con su pariente de sus preocupaciones. Tenga cuídado de no alterar a su pariente o poner a la defensiva; al contrario solicite la participación de su pariente en reconocer y resolver el problema o los problemas presente. Recuerde que la percepción de la situación de su pariente puede ser muy diferente a la suya. Puede usted pensar que su ser querido ya no es capaz de hacerse cargo de ciertas cosas cuando es más cierto que su ser quierdo necesita solamente más tiempo para llevar a cabo aquella tarea. Identifique el tipo de ayuda que su pariente piensa que necesita y que pueda aceptar. Acuerdese de ser sensitiva y afectuosa. Trate a su ser querido con respeto. Preguntese, ¿como me sentiría yo si mi pariente se ocupara de mi vida personal?

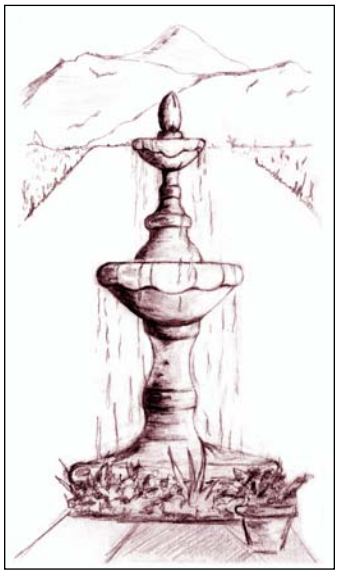
❖ **¿Qué es lo que se requiere para crear un plan de cuídado, que rinda la ayuda y el apoyo que mi ser querido necesita y que este dispuesto en aceptar?**

Junto con su pariente, produzca un plan de cuídado que incluya el apoyo informal y formal.
**Apoyo Informal:** Otros miembros de familia ya pueden estar rindiendo ( o podran querer rendir) cuídado de su pariente. Unase con sus miembros de familia para decidir como trabajar juntos eficazmente como un equípo. También identifique amistades, vecinos y miembros de grupo de fé, asociaciones y sociedades en donde su pariente sea miembro y que puedan estar dispuestos a rendir asistencia. Trate de no abrumar a la gente pero asegurese de discutir con franqueza qué tipo de ayuda ellos pueden querer y poder rendir. Sea tan directa como sea posible y asegure que todos entiendan la situación y compartan sus preocupaciones. Presentese a todos los que vayan a ayudar a su pariente, si a caso no se conocen todavía. Mantenga una lista de sus números de teléfono y sus domicilios. Aviseles que ellos le pueden llamar a cobro a usted a cualquier tiempo del día o noche si ellos estan preocupados por su ser querido. Piense en diferentes formas de como mostrar su agradecimiento y reconocimiento de la ayuda que le estan rindiendo (así como llamadas telefónicas amistosas, cartas de agradecimiento, notas, etc.).
**Apoyo Formal:** El apoyo formal es facilitado por agencias públicas y privadas que ofrecen servicios profesionales de salúd y social para las personas envejecidas. Aprenda los recursos y

servicios disponibles en la comunidad de su pariente. Pongase en contacto con la Agencia de Envejecimiento del Area (Area Agency on Aging) que sirva la comunidad de su pariente para que pueda determinar cual agencia local facilita el tipo de servicio que usted busca. El Concilio de Envejecimiento de Pima (Pima Council on Aging, PCOA) es la Agencia de Envejecimiento del Area que sirve a los adultos envejecidos residentes en el condado de Pima. PCOA puede ayudarle identificar los recursos y servicios locales así como ponerla en contacto con la Agencia de Envejecimiento del Area que sirve otro local geografíco de los Estados Unidos. Otro recurso es el servicio de "Eldercare Locator" (teléfono 1-800-677-1116, lunes a viernes de 9 a.m. a 8 p.m. tiempo este). "Eldercare Locator" es un programa nacional que identifíca la Agencia de Envejecimiento de su Area y otros proveedores de servicio en la comunidad de su pariente. Las comunidades varían extensamente en los tipos de servicios que ofrecen a las personas envejecidas. Algunas consideraciones incluyen: ¿hay servicios profesionales disponibles patrocinados por fondos públicos? Si es esto cierto, ¿hay una lista de espera para los servicios que su pariente necesita? ¿Hay cobros adicionales (co-payments) para estos servicios? ¿Qué servicios privados hay? ¿Qué cobros asociados hay? ¿Cómo estan estos servicios controlados para determinar la calidad de cuídado que se está rindiendo?

### ❖ ¿Qué es lo que necesito hacer para mi misma para prepararme para lo que pueda suceder en el futuro como una cuídadora de larga distancia?

Como una cuídadora de larga distancia, debe usted reconocer qué es lo que puede y no puede hacer. Debe determinar qué tanta asistencia usted está dispuesta y capaz de hacer. Debe de seguír un curso que ajuste con sus propias fuerzas personales, recursos y estilo de vivir. Haga lo mejor de su visita con su pariente. Cada visita debe ser balanceada entre lograr asuntos de negocio, tiempo para disfrutar la compañía de su ser querido por mientras que usted observa y siga la situación sobretoda. Planeé con anticipo qué es lo que quiere llevar a cabo durante su visita, así como: recaudar información medíca, legal y de finanzas; visitar a las agencias locales de servicios sociales, alojamiento residencial o facilidades de vivienda con asistencia; entretener y socializar con su pariente, familia y amistades; recordar tiempos pasados; tener conversaciones de corazón a corazón con su pariente, si es apropiado, etc. Puesto que se requiere llamar frequentemente a su pariente a larga distancia, debe usted averigüar sobre los planes ahorrativos y de descuento de servicios teléfonicos de larga distancia que hay. Debe usted estar preparada para cualquier emergencia y si es necesario estar lista para viajar a cualquier momento. Quizas usted deba considerar: mantener su auto en buenas condiciones de reparación; asegurar que su permiso de conducir un auto esté al corriente igual que su seguro de auto; reunir listas de vuelos, autobús, y tren; y mantener sus documentos de viaje al corriente. Conserve un fondo de ahorro aparte para pagar estos viajes y visitas. Tome en consideración sus otras obligaciones como su salúd, familia y trabajo cuando evalúe sus responsabilidad como cuídador. Quízas tenga que planear antes para poder tomar días personales o tiempo familiar fuera de su trabajo en caso que necesite viajar al lado de su pariente inesperadamente.



### ❖ ¿Qué es lo que debo discutir con mi patrón sobre mis responsabilidades como cuídadora?

Tal vez usted y su patrón quieran establecer un plan de antemano para que usted pueda tener tiempo libre cada otro mes para visitar su pariente. Es mejor discutir sus planes antes con su patrón en lugar de esperar hasta que se presente una situación crítica. Tal vez usted tenga derecho de recibir tiempo familiar libre debido a condiciones médicas (Family Medical Leave). El acto the "Family Medical Leave" de 1993 otorga a los empleados de organizaciones de más de 50 empleados el derecho de tomar hasta doce

semanas libres en ausencia sin pago durante el periodo de doce meses para cuidar un niño(a), un miembro de familia o usted misma(o) con una enfermedad seria y le garantiza su empleo y la continuación de beneficios. Usted puede tomar este permiso de ausentarse en porciones de tiempo por ejemplo unas cuantas horas a la semana, o un día al mes o una semana cada cuántos meses. Averigüe con su patrón para ver: 1) si su tiempo de vacaciones o de enfermedad pueden ser aplicado al tiempo que usted se toma libre, y 2) si debe usted ser empleada en su puesto presente por un cierto tiempo antes de ser elegible para el tiempo libre familiar médico (Family Medical Leave).

### ❖ Hay veces que no estoy segura que mis preocupaciones por mi ser querido son problemas significantes o no. ¿Cómo sé cuando la situación es bastante seria para requerir acción inmediata?

Si usted esta tratando con una situación emergente obvia, su preocupación principal debe ser llegar al lado de su ser querido inmediatamente. Situaciones críticas que requieren su atención inmediata incluyen: un accidente o condición medíca seria, o si nadien se ha podido poner en contacto con su pariente. Si la situación no es una emergencia, puede acaso usted preguntarse las seguientes preguntas para poder ayudarle en determinar si debe usted visitar a su pariente personalmente:

- ¿Qué piensan de la situación las personas en el circulo de apoyo local (formal y informal) de su pariente? ¿Qué recomienda el médico principal de su pariente?
- ¿Qué es el estilo de su pariente? Por ejemplo, tendencias de exagerar o de subestimar la seriedad de una situación.
- ¿Qué es sú estilo? ¿Qué tanta ansiedad y tensión puede usted tolerar antes de decidir en ir?

Consideraciones más practicas pueden incluír:

- ¿Puede usted permitirse el lujo de viajar ahora?
- ¿Tendrá que considerar su trabajo? ¿Ha podido acumular tiempo de vacaciones o de enfermedad? ¿Está usted elegible para el tiempo libre familiar médico (Family Medical Leave)?
- ¿Qué clase de preparaciones ha hecho o necesita hacer para satisfacer su responsabilidades con su cónyuge, hijos y otros miembros de su hogar?

### ❖ He estado pensando en mudarme cerca de mi pariente o mudar mi pariente a mi comunidad o tal vez mudar mi pariente para que viva con mi familia y conmigo. ¿Qué debo considerar antes de hacer una decisión final?

Hable con su pariente, anteriormente de estas alternativas antes que surja una situación crítica. Factores que se deben considerar antes de mover o mudar a un pariente envejecido incluye:

- ¿Quiere su pariente vivir en su ciudad o en su hogar? ¿Qué son las necesidades de su pariente para seguír independiente y familiarizarse con sus amistades y comunidad? Puede ser muy dificil dejar amigos viejos y hacer nuevas amistades en una ciudad diferente.
- ¿Querrá su pariente mudarse a un lugar de vivienda con asistencia formal o otra clase de lugar de vivienda con apoyo formal localizado en su comunidad? Muchas veces las personas envejecidas no quieren vivir en el mismo hogar de sus hijos adultos.
- ¿Qué opciones de viviendas son disponibles para su pariente en su ciudad? ¿Cómo se podra pagar estos modos de vivienda?
- ¿Qué clase de recursos comunitarios patrocinados por fondos públicos existen y están disponibles para ayudar a su pariente si se necesita? Cada estado tiene diferentes servicios disponibles así como el críterio de

elegibilidad para la participación en los servicios y programas.

- Tiene usted que ser muy realistica en lo que se requiere en vivir con su pariente de nuevo en el hogar suyo o en el de su pariente. ¿Será esto la mejor solución para los dos en está situación? Considere invitar a su pariente a vivir con usted por una visita corta para poder determinar si podran mantenerse en el mismo hogar y tener esto como una alternativa.
- ¿Qué es su capacidad emocional y física para poder tratar las necesidades de cuídado de su pariente?
- ¿Qué clase de relación tuvo usted con su pariente en el pasado? ¿Hay conflictos con su pariente que aún no se han resuelto? Si hay, considere qúe resolución es posible antes de mudar a su pariente.
- ¿Qué modificaciones de seguridad, privacidad y espacio se deben hacer en su hogar para complacer las necesidades de su pariente?
- ¿Qué son sus necesidades, las necesidades de su pariente y las necesidades de cualquiera otra persona residiendo en el hogar? ¿Qué diferencias de estilo de vivir existen?

## RECURSOS

- El Concilio de Envejecimiento de Pima (Pima Council on Aging), 8467 E. Broadway Blvd., Tucson, Arizona 85710-4009; Teléfono: (520) 790-7262; www.pcoa.org
- El Consorcio de Cuídadores (Caregiver Consortium); www.arizonacaregivers.org
- Guía de Cuídado (CareGuide); www.careguide.com y toque: "Care for Caregivers"
- La Serie de Planificación Patrimonial (Heritage Planning Series); www.pebco.org
- Autora: Heath, Angela. "El Cuídado a Larga Distancia: Un Guía Supervivencia Para Los Cuídadores A Lejos." ("Long Distance Caregiving: A Survival Guide for Far Away Caregivers.") American Source Books, 1993, 121 pp. $9.95. Llame a 303-980-0580 para ordenar.
- Servicios de "Eldercare Locator"; www.eldercare.gov/elderpage/locator.html
- Edificando Una Salúd Mejor (Building Better Health); www.buildingbetterhealth.com/topic/caregiveld
- Cómo Cuídar (How to Care); www.howtocare.com/caregiving2.htm
- La Asociación Nacional de Cuídadores de Familia (National Family Caregiver Association), 10400 Connecticut Ave. Suite 500, Kensington, MD 20895; Tele: 1-800-896-3650; domicilio electrónico (email): infor@nfcacares.org; web: www.nfcacares.org/FAQ's.html
- Asociación de Personas Americanas Jubiladas (AARP) Soluciones de Vida (LifeAnswers) www.aarp.org/confacts/caregiver/longdistance.html
- PDIA Una Bibliografía de Cuídadores (PDIA Caregiver Bibliography) www.soros.org/death/agingparents.html

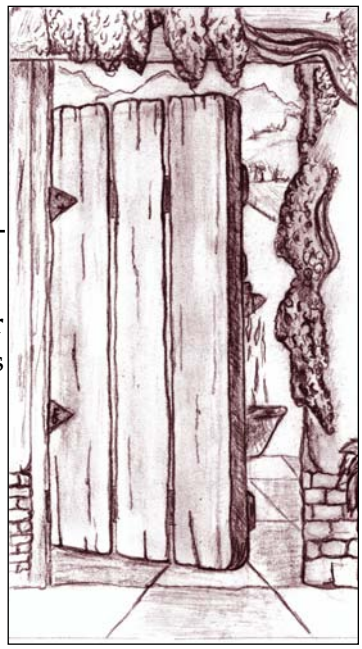
*Preparado para El Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

## CONSEJOS PARA EL CUÍDADOR A LARGA DISTANCIA

- Visite a su pariente frequentemente y haga lo mejor de cada visita. Observe bien la situación de su pariente en cada visita. ¿Nota algo nuevo o diferente en la salud de su pariente o en su estado funcional?
- Discuta sus preocupaciones con otros miembros de la familia. Si es posible, organise una sesión entre familia.
- Permitase tiempo para explorar el "Internet" y otros recursos de información para educarse sobre sus preocupaciones médicas, recursos y servicios locales, e información de cuídador.
- Establezca un rutina. Mantenga contacto regular, si no es por teléfono ya sea por cartas o mensaje electronico ("e-mail"). Mande cartas sobre eventos en su vida por mientras que también incluya recordatorios amigables sobre preparaciones o cosas que su pariente quízas haga olvidado o está demorando. Su apoyo emocional es importante y sus consejos en ayudar a su pariente hacer decisiones es una forma de cuídado. Trate de hablar con sus dos padres en la misma conversación teléfonica haciendo que la tercera persona use el teléfono de extensión.
- Establezca una lista de números de teléfono, mensaje electronico ("e-mail") y domicilios de correspondencia de parientes y amistades para mantenerlos informados.
- Apunte notas especialmente sobre puntos importantes, fechas y tiempos de conversaciones con profesionales de salud y ayudantes personales.
- Crea un diario para mantener información importante así como notas y observaciones sobre el estado de salud de su pariente, nombres y información de contacto de ayudantes, informacion de viajes, información legal, financiero y de seguros, etc.
- Pongase en contacto con la Agencia de Envejecimiento del Area ("Area Agency on Aging") en la comunidad de su pariente. También obtenga una copia de las Paginas Amarillas ("Yellow Pages") de la comunidad o ciudad de su pariente. Le podra ayudar en localizar servicios y agencias locales en la comunidad de su pariente por mientras que usted este en su hogar. Si pide usted un guía que sea enviado por correo podrá ser muy caro. Procure recoger una copia gratis en los locales de servicio telefonicos cuando visite a su pariente. También puede localizar las Paginas Amarillas ("Yellow Pages") y Paginas Blancas ("White Pages") en el "Internet:" www.Smartpages.com
- Examine las características del hogar de su pariente que puedan necesitar cambios o modificaciones para mantener ambulanción segura y otras actividades.
- Aprenda los diferentes productos y aparatos que hay de asistencia que puedan ayudar a su pariente. Productos como el Sistema de Emergencia de Respuesta Personal donde la persona puede llamar por asistencia de servicios emergentes cuando oprime un botón en el aparato chico que lleva en su persona.
- Tome en cuenta las obligaciones y expectaciones ocultas puestas en un cuídador por la sociedad y cultura que puedan contribuír pensamientos de culpa y aislamiento.
- No sienta que tiene que seguir un curso de solución si éste método no esta trabajando. Sea flexible.
- Confíe en sus presentimientos y sus intuiciones. Hay veces los seres que queremos se contienen en decirnos información que nos pueda alterar.
- Aprenda en dar cortésmente para que sus padres no presientan sensaciones de resentimiento y hostilidad.

# MEDICAL VISITS: SCHEDULING, PREPARATION AND SUPPORT

*helping older relatives or friends to become active participants in their own health care*



## FREQUENTLY ASKED QUESTIONS ABOUT HELPING RELATIVES WITH MEDICAL VISITS

As a caregiver you can provide valuable assistance in preparing and accompanying your relative to a medical visit. You can mention concerns that your relative wanted to discuss with the doctor but may have forgotten to ask as well as record what was said for your relative to review later.

### ❖ How can I assist my relative in preparing for initial visits with a physician?

Prior to the medical visit, suggest that your relative gather or write down the following types of information:

- If your relative is visiting a physician for the first time, bring a list of names, addresses and telephone numbers of all treating health professionals along with dates of service that are most significant to your relative's medical history.
- Make a list of the names and dosages of current medications, including over-the-counter drugs, herbals and vitamin supplements. However, many older persons bring their medications in a bag to the medical visit rather than making a list.
- The names and telephone numbers of emergency contact persons.
- A list of allergies to drugs, foods and other substances.
- The most recent Health Insurance Card(s): make sure your relative's coverage is accepted by a particular physician BEFORE making the appointment.
- A description of current symptoms, including: when each first appeared, severity, whether symptoms are the same as before, self-care (what your relative is doing at home to treat the problems), and what, if anything, makes the symptoms better or worse.
- Questions about sensitive subjects that your relative may want to discuss such as: sexuality, depression, incontinence, memory problems, etc. Be aware that your relative may be uncomfortable about openly discussing these topics with you as well as the doctor. It may help if you explain to your relative that doctors are accustomed to talking about these subjects and will try to ease the embarrassment or discomfort that may arise when speaking of these personal concerns. If you are your relative's designated health care agent (health care power of attorney) you may want to inform the physician about your relative's concerns prior to the visit. A good doctor will take your relative's concerns about these topics seriously and not dismiss them as a normal part of aging.
- Copies of advance directives, if any, including: living will, health care power of attorney and any other prehospital directives. Your relative's primary physician, specialist and hospital should have a copy of any advance directives.
- Lifestyle factors that may affect treatment options such as: cigarette smoking, alcohol consumption, problems sleeping, appetite changes, poor concentration and driving difficulties.

### ❖ What should my relative learn about the physician's routine and medical office protocol to improve access to care when needed?

It is important for your relative to become familiar with the physician's routine and office protocol in order to obtain timely care and information. Your relative may consider asking the office manager or other administrative staff the following questions:

- Will the physician accept your relative's type of health insurance (Medicare, HMO, Blue Cross Blue Shield, Medicap policies, etc.) as payment for service? Will my insurance cover the entire cost of the visit?
- What days/hours is the office open? Most doctors are not available 24 hours a day, seven days a week so it is important that your relative find out who to call after hours or who is available to answer questions if the doctor is away.
- Are walk-ins seen? If urgent care is needed can your relative be seen within 24 hours? If routine care is needed can your relative be seen within a week? Is there a penalty fee for no shows or cancellation of visits less than 24 hours in advance? What is the typical length of time reserved for a routine office visit?
- What is the best time to make routine, non-urgent phone calls?
- If 911 has been called in a medical emergency, how is the physician notified of the emergency situation?
- Who should your relative call if they have questions about a treatment, procedure or side effects from a prescribed medication?
- Who will have a current copy of your relative's medical file, including information about your relative's conditions, medications and treatment plan?

### ❖ How can I help my relative on the day of the medical visit?

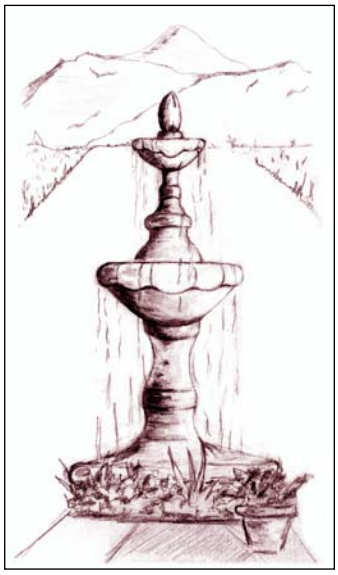
On the day of the medical visit make sure your relative is as relaxed as possible and feels "in control." If you will be accompanying your relative, you may want to arrive at your relative's residence at least one hour prior to the required travel time to the physician's office. This extra time will give both you and your relative a chance to review the reasons for the visit, talk about expectations and prioritize the 3 most important concerns to be addressed. Remind your relative to consider both physical problems as well as emotional concerns. Also, ask how you can be of most help during the medical visit, i.e., what your relative would like and not like you to do. Make sure you arrive on time or come early if requested. Allow for extra time if you are unfamiliar with the location of the medical office and/or if your relative has a physical impairment that makes transferring or maneuverability difficult.

### ❖ Can I discuss my relative's health condition with the physician and other health professionals?

Your relative must specify who is authorized to have access to his or her medical information. An individual has certain rights under federal privacy standards about how medical information may be used and made known to others, including:

- the right to request restrictions on the use and disclosure of your protected health information,
- the right to receive confidential communications concerning your medical conditions and treatments,
- the right to inspect and copy your protected health information, and
- the right to an accounting of how and to whom your protected health information has been disclosed.

If you are the designated health care agent (health care power of attorney) for your relative, then you have authorization to discuss your relative's health condition with treating physicians and other health care practitioners. If you are not the designated health care agent, your relative must tell treating physicians and other practitioners that you may talk to them about your relative's medical condition and treatment.



### ❖ Should my relative always speak directly with the physician regarding any health concern?

Your relative may not always need to talk to the physician directly about basic questions. The nurse, nurse practitioner or physician assistant who may

work with the doctor are usually more available and can spend more time answering questions. Also, they can look-up information in your relative's medical file and consult with the doctor as needed. However, your relative should not hesitate to call the physician about any health concern. The doctor will return the call but it might take longer to obtain a response. Your relative should consider speaking directly with the physician or designated staff member to discuss:

- Diagnoses or a change in treatment.
- Concerns about a new symptom.
- How to use a new medication, i.e., how often and how long should the drug be taken, and what might happen if the medication is not taken as prescribed.
- Potential negative side effects from prescribed medications and adverse drug interactions (if any) when taken with other medications.
- Test results.
- Referrals to specialists (doctors in different areas of medicine).

Some practical considerations include:

- Ask the office receptionist when would be the best time to reach the doctor. Some doctors have specific hours when they take calls. Find out what these times are and call then.
- If your relative chooses to leave a message, it should state the number to call and the best times to be reached. Make sure your relative leaves all applicable telephone numbers, i.e., home, work, and cellular phone.
- Your relative may want to ask if it is possible to communicate with the physician by sending e-mails about non-urgent health concerns.

### ❖ What should my relative say when contacting the physician about a health problem?

Some general guidelines that your relative should follow when calling the physician about a health concern are:

- Be prepared before calling. Have your relative write down a short description of the problem, the reason for calling, a short symptom list and no more than three questions to ask the physician.
- Be concise and stick to the issues.
- If your relative does not understand something, ask the doctor to explain it again. Repeating what was said may help your relative make sure they heard it correctly.
- Your relative should call the physician if a new medication or an urgent refill of a current medication is needed or if the pharmacy will not refill a prescribed medication. Otherwise, your relative's pharmacy will contact the prescribing doctor as necessary to refill current medications. Before calling the physician, your relative should have on hand the telephone number and location of the pharmacy that will be used. Call during regular office hours and before there is only one pill left.

### ❖ Time and again, the doctor or the doctor's staff does not return my relative's telephone calls. What can my relative do to make sure the doctor or doctor's staff responds in a timely manner?

Depending on the type of relationship your relative has with the doctor, she/he may want to consider changing doctors. If your relative has formed a trusting and long-standing relationship with the doctor, working out the problem may be more useful than looking for a new doctor. Misunderstandings arise in any relationship, including between patient and doctor. Suggest that your relative be direct when speaking to the doctor or the doctor's staff about the problem. For example, your relative may want to say something like, "I realize that you are very busy and take

care of a lot of patients, but I get upset and frustrated when I have to wait for days for you to return my call. How can we solve this problem?" If the doctor or doctor's staff continues to brush off your relative's concerns, then it may be in your relative's best interest to look for another doctor. Remember, no matter how frustrating a situation becomes, your relative will be more likely to obtain the care that is needed by clearly stating the problems, being persistent and sincere.

## RESOURCES

- Pima Council on Aging
  8467 E. Broadway Blvd.
  Tucson, Arizona 85710-4009
  Phone: (520) 790-7262; www.pcoa.org
- Caregiver Consortium; www.arizonacaregivers.org
- Talking with Your Doctor: A Guide for Older People.
  National Institute on Aging.
  www.nia.nih.gov/health/pubs/talking/talkwithdoc.pdf
- Caregiving: Communicating with Health Professionals
  AARP.
  www.aarp.org/confacts/caregive/healthprof.html
- Communicating with Your Aging Parent's Physician.
  CareGuide.
  www.coordinatedcare.com/Careguide/index.jsp
  Click on: Care for Caregivers
  Go to: Featured Topics
- Choosing a Doctor. Age Page.
  www.nia.nih.gov/health/agepages/choose.htm
- Communicating with Health Care Professionals.
  Beth Israel Medical Center.
  www.stoppain.org/caregivers/communicating.html
- Schilling, L., et al; "The Third Person in the Room:
  Frequency, Role and Influence of Companions
  During Primary Care Medical Encounters"
  The Journal of Family Practice, August 2002; 51:685-690
- Frequently Asked Questions About Medical Ethics.
  American Medical Association
  515 N. State St.
  Chicago, IL 60610
  Phone: (312)464-5000; www.ama-assn.org
  Click on: Medical Ethics-Frequently Asked Questions

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# MEDICAL VISITS: SCHEDULING, PREPARATION AND SUPPORT

*helping older relatives or friends to become active participants in their own health care*

As a caregiver you can provide valuable assistance in preparing and accompanying your relative to a medical visit. You can mention concerns that your relative wanted to discuss with the doctor but may have forgotten to ask as well as record what was said for your relative to review later.

## INITIAL MEDICAL VISITS

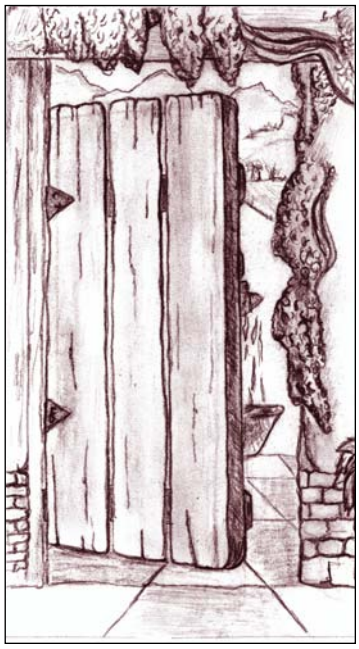
Prior to the medical visit, suggest that your relative prepare the following information:

- Bring a list of names, addresses and telephone numbers of all treating health professionals along with dates of service that are most significant to your relative's medical history.
- Make a list of the names and dosages of current medications, including over-the-counter drugs, herbals and vitamin supplements. Rather than making a list, bring the medications in a bag to the medical visit.
- The names and telephone numbers of emergency contact persons.
- A list of allergies to drugs, foods and other substances.
- The most recent Health Insurance Card(s): make sure your relative's coverage is accepted by a particular physician BEFORE making the appointment.
- A description of current symptoms, including: when each first appeared, severity, whether symptoms are the same as before, self-care (what your relative is doing at home to treat the problems), and what, if anything, makes the symptoms better or worse.
- Questions about sensitive subjects that your relative may want to discuss such as: sexuality, depression, incontinence, memory problems, etc. Be aware that your relative may be uncomfortable about openly discussing these topics with you as well as the doctor. If you are your relative's designated health care agent (health care power of attorney) you may want to inform the physician about your relative's concerns prior to the visit.
- Copies of advance directives. Your relative's primary physician, specialist and hospital should have a copy of any advance directives.
- Lifestyle factors that may affect treatment options such as: cigarette smoking, alcohol consumption, problems sleeping, appetite changes, poor concentration and driving difficulties.

## OFFICE PROTOCOL AND ROUTINE

Your relative may consider asking the office manager or other administrative staff the following questions:

- Will the physician accept my type of health insurance? Will my insurance cover the entire cost of the visit?
- What days/hours is the office open? Who do I call after hours or who is available to answer questions if the doctor is away.
- Are walk-ins seen? If I need urgent care can I be seen within 24 hours? If it is a routine visit, can I be seen within a week? Is there a penalty fee for no shows or cancellation of visits less than 24 hours in advance? What is the typical length of time reserved for a routine office visit?
- What is the best time to make routine, non-urgent phone calls?
- If 911 has been called in a medical emergency, how is the physician notified of the emergency situation?
- Who should I call if I have questions about a treatment, procedure or side effects from a prescribed medication?
- Who has a current copy of my medical file?



## HELPING ON THE DAY OF THE VISIT

Make sure your relative is as relaxed as possible and feels "in control." If you will be accompanying your relative, arrive at your relative's home at least one hour early. This extra time will give both you and your relative a chance to review the reasons for the visit, talk about expectations and prioritize the 3 most important concerns to be addressed. Ask how you can be of most help during the medical visit, i.e., what your relative would like and not like you to do. Make sure you arrive at the medical office

on time or come early if requested. Allow for extra time if you are unfamiliar with the location and/or if your relative has a physical impairment that makes transferring or maneuverability difficult.

## CONFIDENTIALTY OF HEALTH INFORMATION

Your relative must specify who is authorized to have access to his or her medical information. An individual has certain rights under federal privacy standards about how medical information may be used and made known to others, including:

- the right to request restrictions on the use and disclosure of your protected health information,
- the right to receive confidential communications concerning your medical conditions and treatments,
- the right to inspect and copy your protected health information, and
- the right to an accounting of how and to whom your protected health information has been disclosed.

If you are the designated health care agent for your relative, then you have authorization to discuss your relative's health condition with treating physicians and other health care practitioners. If you are not the designated health care agent, your relative must tell treating physicians and other health practitioners that you may talk to them about your relative's health.

## WHEN TO TALK WITH THE PHYSICIAN

Your relative may not always need to talk to the physician directly about basic questions. Health professionals who assist the doctor can spend more time answering questions. However, your relative should consider speaking directly with the physician or designated staff member to discuss:

- Diagnoses or a change in treatment.
- Concerns about a new symptom.
- How to use a new medication, i.e., how often and how long should the drug be taken, and what might happen if the medication is not taken as prescribed.
- Potential negative side effects from prescribed medications and adverse drug interactions (if any) when taken with other medications.
- If an urgent refill of a current medication is needed. Otherwise, your relative's pharmacy will contact the prescribing doctor as necessary to refill current medications.
- Test results.
- Referrals to specialists (doctors in different areas of medicine).

Some practical considerations include:

- Ask the office receptionist when would be the best time to reach the doctor and call then.
- If your relative chooses to leave a message, it should state the number to call and the best times to be reached.
- Ask if it is possible to communicate with the physician by sending e-mails about non-urgent health concerns.

## GUIDELINES FOR CALLING

Some general guidelines that your relative should follow when calling the physician about a health concern are:

- Be prepared before calling. Have ready a short description of the problem, a short symptom list and no more than three questions to ask the physician.
- Be concise and stick to the issues.
- If your relative does not understand something, ask the doctor to explain it again.
- Have in hand the telephone number and location of the pharmacy that will be used. Call during regular office hours and before there is only one pill left.

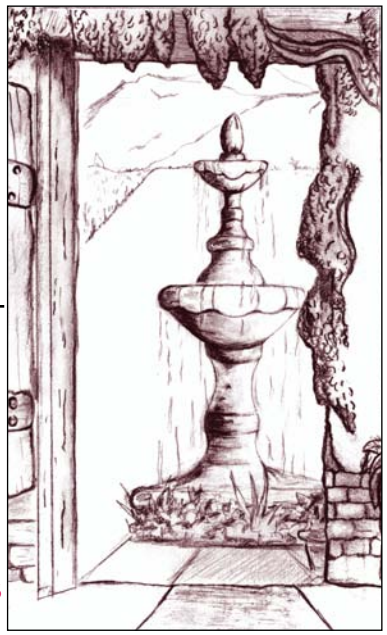
## NOT ANSWERING PATIENT CALLS

Misunderstandings arise in any relationship, including between patient and doctor. If your relative has formed a trusting and long-standing relationship with the doctor, working out the problem may be more useful than looking for a new doctor. Suggest that your relative be direct when speaking to the doctor or the doctor's staff about the problem, such as: "I realize that you are very busy and take care of a lot of patients, but I get upset and frustrated when I have to wait for days for you to return my call. How can we solve this problem?" If the doctor or doctor's staff continues to brush off your relative's concerns, then it may be in your relative's best interest to look for another doctor.

Remember no matter how frustrating a situation becomes, your relative will be more likely to obtain the care that is needed by clearly stating the problems, being persistent and sincere.

# VISITAS MEDICAS: CITAS, PREPARACION Y APOYO

*Ayudando a nuestros parientes o amigos de edad avansada a ser participantes activos en su propio cuidado medico*



## PREGUNTAS FRECUENTEMENTE PREGUNTADAS ACERCA DE COMO AYUDAR A NUESTROS PARIENTES CUANDO TENGAN VISITAS CON EL MEDICO

Como proveedor de cuidado usted puede proveer valioza asistencia en acompañar y preparar a su pariente para tener una visita con el doctor. Usted puede mensionar preguntas que su pariente quiere hablar con el doctor pero que tal vez se le alla olvidado preguntar. Tambien escriba las respuestas del doctor a las preguntas para que su pariente pueda repasarlas despues.

### ❖ Como puedo ayudar a mi pariente para prepararse para sus primeras citas con el doctor?

Antes de ir a la cita con el doctor, sujiera a su pariente que escriba las siguientes clases de informacion:

- Si su pariente esta visitando al doctor por primera vez, traiga una lista de nombres, direcciones y numeros de telefono de todos los doctores con quien a tenido citas y las fechas de las citas y los tipos de servicios que recivio que sean significantes a la historia medica de su pariente.
- Haga una lista con los nombres y docis de sus recientes medicamentos incluyendo medicinas sin receta medica, remedios herbales y vitaminas. Muchas personas de edad avansada ponen todas sus medicinas en una bolsa y las llevan con ellos a la cita con el doctor en vez de hacer una lista.
- Los nombres y numeros de telefono de personas que pueden ser contactadas en caso de una emergencia.
- Una lista de alerjias a medicinas, comidas o otras substancias.
- La tarjeta de aseguranza mas reciente: este seguro que su pariente tenga un seguro de salud aceptado por el doctor ANTES de hacer la cita.
- Una descripcion de simptomas recientes, incluyendo: cuando cada uno aparecio, la seriedad, si los simptomas son los mismos de antes, cuidado propio (lo que su pariente esta haciendo en su hogar para cuidarce a si mismo), y que es lo que ayuda o empiora los simptomas.
- Preguntas de temas sensibles que su pariente talvez desee pregunar como: sexualidad, deprecion, incontinecia, problemas con la memoria, etc. Este informado de la posibilidad que su pariente talvez se sienta incomodo hablando abiertamente de estos temas con usted on con el doctor. Le podria ayudar usted a su pariente si le mensiona que los doctores estan acostumbrados a hablar de estos temas tan sensibles. Si usted es el proveedor de cuidado para su pariente (por la ley) talvez quiera usted informar al doctor de las preguntas que su pariente tiene. Un buen doctor no tomara las preguntas como parte del proceso de la vejez sino que las tomara muy enserio.
- Copias de directivos por adelantado, si existen, incluyendo: testamento, provicion de cuidado por la ley, y cualquier directivo de cuidado por adelantado para el hospital. El doctor de su pariente, especialistas medicos, y el hospital deben tener una copia de sus directivos por avansado.
- Habitos de la vida cotidiana que puedan afectar sus tratamientos como: fumar cigarros, beber alcohol, problemas para dormir, cambios en el apetitio, pobre concentracion y dificultades para manejar.

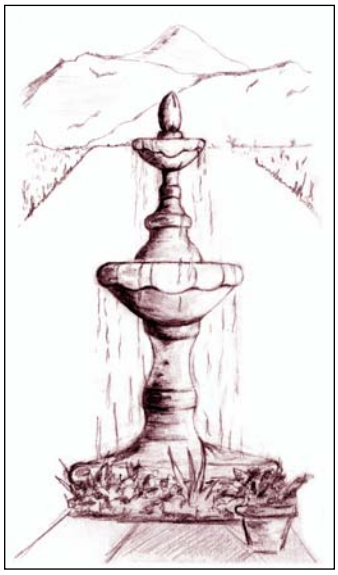
### ❖ Que es lo que mi pariente necesita saber acerca de los procedimientos rutinarios del doctor y procedimientos de la oficina para poder mejorar acceso a cuidado cuando sea necesario?

Es importante que su pariente se familiarice con los procedimientos rutinarios del doctor y procedimientos de la oficina para poder obtener cuidado y informacion en el tiempo necesario. Su pariente puede considerar preguntarle al manejador de la oficina o otros trabajadores administrativos las siguientes preguntas:

- El doctor aceptara el tipo de aseguranza de su pariente ( Medicare, HMO, Cruz Azul Escudo Azul, Polizas de Medicap, etc.) como pago por sus servicios? Mi aseguranza cubrira por completo el costo de la consulta?
- Que dias/horas estara la oficina abierta? La mayoria de los doctores no estan disponibles las 24 horas del dia, siete dias de la semana a si que es importante que su pariente se de cuenta a quien podra hablar despues de que se termine el horario del doctor o quien estara disponible para contestar preguntas cuando el doctor este fuera.
- Se reciven a pacientes sin cita? Si se necesita cuidado urgente sera posible que el doctor vea a su pariente en 24 horas? Si cuidado rutinario es necesario, sera posible que el doctor vea a su pariente en una semana? Existe un cargo por castigo por cancelar citas con menos de 24 horas de anuncio o por no llegar a la cita? Cual es el tiempo normalmente reservado para una visita con el doctor rutinaria?
- Cual es el major tiempo para hacer llamadas rutinarias sin emerjencia?
- Si 911 ha sido llamado por causa de una emergencia, como es que el doctor puede ser notificado de la emerjencia?
- A quien debe su pariente llamar con preguntas del tratamiento, procedimientos o efectos secundarios a la medicina recetada?
- Quien tendra una copia del expediente medico mas reciente de su pariente, incluyendo informacion acerca de la condicion de su pariente, medicamentos y plan de tratamiento?

### ❖ Como puedo ayudar a mi pariente en el dia de la cita con el doctor?

En el dia de la cita con el doctor este seguro/a que su pariente este lo mas relajado/a que sea posible y que se sienta "en control." Si usted va a acompañar a su pariente, talvez seria lo major que recojiera a su pariente una hora antes de la cita con el doctor. Este tiempo extra les dara la oportunidad a usted y a su pariente para repasar las rasones para la cita y hablar de lo que esperan y dar prioridad a las tres preguntas mas importantes. Recuerdele a su pariente que hable con el doctor de sus problemas fisicos y tambien sus problemas emocionales. Tambien, pregunte como es que usted puede ser de major ayuda durante la cita con el doctor, por ejemplo, lo que a su pariente le gustaria o no le gustaria que usted hiciera. Asegurece de llegar a tiempo o de llegar antes de la cita si se lo han pedido. Permita tener mas tiempo si no esta seguro de la direccion de la oficina o si su pariente tiene un impedimiento fisico que hace que tenga dificultades para moverse de un lado a otro.



### ❖ Puedo yo hablar con el doctor de mi pariente o otros profecionales medicos acerca de la condicion de salud de mi pariente?

Su pariente debe especificar quien esta autorizado para tener acceso a su informacion medica. Cada individuo tiene ciertos derechos bajo la ley federal de privacidad acerca de como es que su informacion medica puede ser compartida con otros, incluyendo:

- el derecho de poner restricciones en el uso y la revelacion de su informacion medica,
- el derecho a recivir platicas confidencialmente acerca de su informacion medica, condiciones y tratamientos,
- el derecho de inspecionar y copiar su informacion de salud,
- el derecho de saber a quien se le ha compartido su informacion de salud.

Si usted es la persona asignada por la ley para cuidar de su pariente, entones usted tiene la autorizacion para hablar acerca de la condicion de salud de su pariente con el doctor y otros profecionales de medicos. Si usted no es la persona asignada por la ley, su pariente tiene que decirle al doctor y otros profecionales medicos que usted puede hablar con ellos acerca de la condicion medica de su pariente y sus tratamientos.

### ❖ Debe mi pariente siempre hablar directamente con el doctor acerca de cualquier pregunta de su salud?

Su pariente tal vez no siempre tenga que hablar con el doctor directamente acerca de preguntas basicas. La enfermera, o ayudante del doctor que trabajan con el doctor normalmente estan mas disponibles y pueden pasar mas tiempo contestandole sus preguntas. Tambien, pueden buscarle informacion en el expediente de su pariente y consultar con el doctor cuando sea necesario. Aunque, su pariente no debe dudar en hablarle al doctor cuando tenga dudas acerca de su salud. El doctor le regresara la llamada pero es posible que se tarde mas tiempo en recivir una respuesta. Su pariente debe considerar hablar con el doctor directamente o un trabajador asignado para hablar de:

- Diagnostico o cambios en el tratamiento.
- Precupacion acerca de un simptoma nuevo.
- Como usar un nuevo medicamento, por ejemplo, cada cuando y y por cuanto tiempo debe tomarse la medicina, y que puede pasar si la medicina no es tomada como fue recetada.
- Posibles efectos secundarios de medicamentos recetados y malas reacciones a combinaciones de medicamentos cuando se toman juntos.
- Resultados de pruebas.
- Remision con especialistas (doctores en otras areas de medicina).

Algunas consideraciones practicas incluyen:

- Pregunte a la recepcionista de la oficina cuando seria el major tiempo para hablar con el doctor. Algunos doctores tienen horarios fijos en los que aceptan llamadas. Pregunte cundo son estos horarios y hable durante esos tiempos.
- Si su pariente escoje dejar un mensaje, debe mencionar al numero que debe llamar y cuales son los horarios en los que usted estara disponible.
- Su pariente tal vez quiera preguntar si es posible comunicarce con el doctor por correo electronico, mandando mensajes al doctor acerca de preguntas de salud que no son emerjencias.

### ❖ Que es lo que mi pariente debe decir cuando hable con el doctor acerca de un problema medico?

Algunas sujerencias generales que su pariente debe seguir cuando llame al doctor para hacerle unas preguntas acerca de su salud son:

- Este preparado antes de llamar. Pida a su pariente que escriba una corta descripcion acerca de su problema, la razon por la que esta llamando, una lista corta de los simptomas y no mas de tres preguntas que preguntarle al doctor.
- Sea conciso y mantengace en el tema.
- Si su pariente no entiende algo, pidale al doctor que lo vuelva a explicar. La repeticion de la explicacion puede ayudar a su pariente a reconoser si lo escucho corectamente.
- Su pariente deberia hablarle al doctor si necesita mas medicamento o si la farmacia no le da mas medicamento. De otra manera la farmacia llamara al doctor cuando sea necesario que le den mas medicamentos. Antes de llamar al doctor su pariente deberia tener la direccion y el telefono de la farmacia a la mano. Llame al doctor durante horario regular y antes de que le quede solamente una pastilla.

❖ **Vez traz vez, el doctor o los trabajadores del doctor no le regresan las llamadas telefonicas a mi pariente. Que puede hacer mi pariente para asegurar que el doctor o los trabajadores del doctor regresen las llamadas en una manera efectiva?**

Dependiendo del tipo del relacion que su pariente tenga con el doctor, el/ella puede considerar cambiar de doctor. Si su pariente a formado una relacion larga de confianza con su doctor, tratar de solucionar el problema puede que sea major que buscar otro doctor. Malos entendidos surjen en cualquier relacion, incluyendo entre doctor y paciente. Sujiera que su pariente sea directo/a cuando se comunique con el doctor o los trabajadores del doctor acerca del problema. Por ejemplo, su pariente podria decir algo como, " Yo entiendo que usted esta muy ocupado/a y que cuida de muchos pacientes, pero me siento mal y frustrado/a cuando tengo que esperar por dias para recivir su llamada. Como podemos resolver este problema?" Si el doctor o los trabajadores del doctor continuan ignorando las preocupaciones de su pariente, entonces es posible que sea en los mejores intereses de su pariente el buscar otro doctor. Recuerde, no importa que frustrante se ponga la situacion, su pariente podra obtener el cuidado que es necesario al explicar claramente los problemas, siendo persistente y sincero/a.

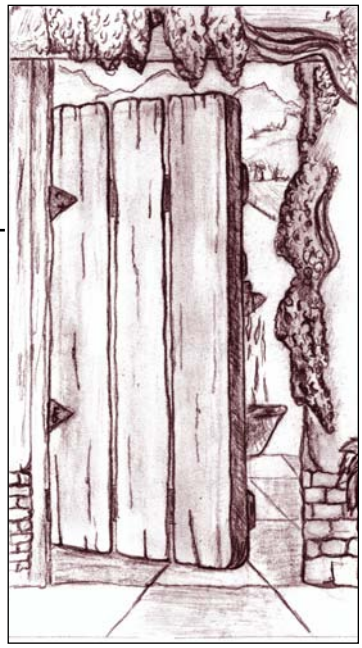
## RECURSOS

- Concilio de Pima para los Ancianos
  8467 E. Broadway Blvd.
  Tucson, Arizona 85710-4009
  Telefono: (520) 790-7262
  www.pcoa.org
- Consorcio de Proveedores de Cuidado
  www. Arizonacaregivers.org
- Hablando con su Doctor: Una Guia para Personas de Edad.
  Instituto Nacional en Ancianos.
  www.nia.nih.gov/health/pubs/talking/talkwithdoc.pdf
- Proveedor de Cuidado: Comunicandoce con
  Profecionales Medicos AARP.
  www.aarp.org/confacts/caregive/healthprof.html
- Comunicandoce con el Doctor de sus
  Padres que son Ancianos,
  Guia de Cuidado Centro Medico Beth Israel
  www. Stoppain.org/caregivers/communicating.html
- Schilling, L., et al; "La Tercera Persona en el Cuarto:
  Frecuencia, Rol y influencia de Compañeros
  Durante Encuentros con el Doctor para Cuidado Primordial"
  Boletin de Practicas Familiares, agosto 2002; 51:685-690
- Preguntas Frecuentemente Preguntadas
  Acerca de Eticas Medicas
  Asociacion Americana de Medicos
  515N. State St.
  Chicago, IL 60610
  Telefono: (312) 464-5000; www.amassn.org
  Oprima en : Etica Medica-Preguntas Frecuentemente Preguntadas

*Preparado para el Concilio de Envejecimiento de Pima (Pima Council on Aging)*
*por el Centro de Envejecimiento de Arizona (Arizona Center on Aging),*
*de la Universidad de Arizona®*

# COMMUNICATING WITH PHYSICIANS AND OTHER HEALTH PROFESSIONALS

*helping older relatives or friends to become active participants in their own health care*



## FREQUENTLY ASKED QUESTIONS ABOUT COMMUNICATING WITH HEALTH PROFESSIONALS

In your caregiver role it is important to support and encourage your relative to effectively communicate with treating physicians and other health professionals. Always respect how much your relative is willing to share with you about their health condition.

### ❖ What are the major communication barriers between older patients and physicians?

Older persons are less likely to ask questions and more likely to "follow doctor's orders" even if they don't totally understand the purpose of treatments or tests recommended or the medications prescribed. Many times older patients prefer to rely on the doctor's expertise than to be involved in the decision making process. Another barrier is that communication takes time and insurance companies rarely pay for as much time with the doctor as older patients may want and need. Also, when a caregiver accompanies the older person to a medical visit the doctor or doctor's staff may be inclined to speak solely to the caregiver and not the older person. This may make the older person feel invisible and powerless over decisions about their own health care. Moreover, attitudes about "aging" may also prevent successful communication between health practitioners and older persons. Physical problems affect persons of any age, and, after all, an "aged" person is only someone who has lived longer than a younger person. To really have good communication, your relative and the health professional should believe that ill health is not something to expect as part of growing older.

### ❖ How can I help my relative take more of an active role in communicating with the physician?

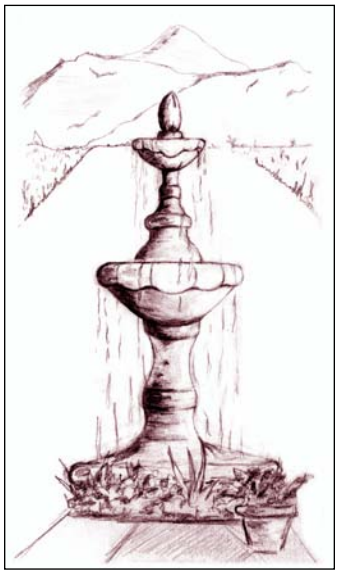
Speak to your relative about viewing the relationship with the physician as a "partnership" where both partners must share information to achieve the best possible care. Being a good partner means to: take good care of yourself; practice medical self-care at home; at the first sign of a health problem write down the symptoms; play an active role in the medical visit by asking questions and stating your preferences for care and taking responsibility for your own health. This includes asking questions if the doctor's explanations or instructions are unclear, bringing up problems even if the doctor doesn't ask and letting the doctor know if a treatment isn't working. You can help your relative make a list of questions and concerns. Many older persons bring a tape recorder to medical visits to make sure they can correctly recall what was said. Suggest that your relative ask the physician the following questions: What illness do I have? What are my treatment options (drugs or alternative approaches)? What should I expect to happen with or without treatment? Will my insurance cover the entire cost of the treatment? Is there written information about the illness, suggested treatments and medications? What is the best way to contact the physician (phone, e-mail, etc.)?

If the doctor prescribes a medication suggest that your relative ask the following: What is the name of the medication? Is a generic form of the prescribed medication available? How often and how long should the drug be taken? What might happen if the medication is not taken as prescribed? What foods, other medications, or activities should be avoided while taking it? What are the possible side effects of taking the medication as prescribed (drowsiness, constipation, etc.)?

## ❖ Are there communication tips that will help prepare my relative for a medical visit?

Before the visit, you may want to discuss with your relative the following tips about sharing information:

- Being honest – It is very important to be as honest as possible about what is happening both emotionally and physically. Suggest that your relative try not to say what the doctor might want to hear; for example, that he/she is exercising regularly and eating less fatty food. While this may be natural, it is not in your relative's best interest. The doctor can provide the best treatment only if your relative says what is really going on.
- Sticking to the point – Routinely, each patient is scheduled for a specified amount of time. Your relative can make the best use of their time by giving the doctor a brief description of the symptom, when it started, how often it happens, and if it is getting worse or better. Make sure your relative has requested enough time to discuss their concerns and conditions. When scheduling an appointment your relative should convey that a longer than normal visit will be needed. Your relative should not leave until they have a clear understanding of diagnosis, treatment and what is needed to recover and stay healthy.
- Asking about options to conventional treatment – Many common conditions, if not very serious, can be treated without medications. The doctor may recommend that your relative first consider trying exercise, good nutrition, stress reduction methods, herb supplements and vitamins as well as other non-drug physical or manual therapies to alleviate the symptoms.
- Learning more about medical tests and other procedures – Your relative may require blood tests, x-rays or other procedures so that the physician can find out what is wrong or learn more about the illness and identify treatment options. Suggest that your relative ask the doctor to explain why the test or procedure is important, what it will cost and how to prepare for the test (not eating or taking prescribed medications for a period of time prior to the test). Your relative may want to ask the doctor for any written information that describes the test or procedure. Remind your relative to find out when to expect (and how to obtain) test results, if the doctor will be available to answer any questions that may arise, and if a follow-up visit will be needed. Your relative may request a written copy of the test results. If the test is performed by a specialist, your relative should ask that test results be sent to their primary physician.
- Asking the doctor about the diagnosis and what to expect – Your relative may want to ask the doctor the following questions: What may have caused the condition? Will it be permanent? How is the condition treated or managed? What will be the long term effects on my life? How can I learn more about my illness/condition?
- Understanding what the physician has said – If your relative does not understand something, then ask the doctor to explain it again. Repeating what was said may help your relative make sure they heard it correctly.



## ❖ How can my relative find out about a doctor's educational background and training?

Your relative may want to know about a physician's training and experience including whether or not the doctor is Board Certified and in what field. Doctors who are Board Certified have had additional training specializing in a certain field/area of medicine. Board Certification is one way for your relative to tell about a doctor's expertise, but it does not guarantee availability when needed nor does it measure ability to communicate effectively.

For information about a physician's credentials, education and training, disciplinary history and malpractice/criminal information contact:

- Arizona Medical Board, 9545 E. Doubletree Ranch Rd, Scottsdale, AZ 85258-5539; Phone: (480) 551-2700; or toll free (877)255-2212; www.bomex.org
  Click on: AZDOCInfo: Physician, Resident & PA Search

- Pima County Medical Society, 5199 E. Farness Dr., Tucson, AZ 85712; Phone: (520) 795-7985; www.pimamedicalsociety.org

For information about Board Certified Medical Specialists including a description of the medical specialty, the medical specialist's credentials, education and training as well as access to a directory of certified specialists, contact:

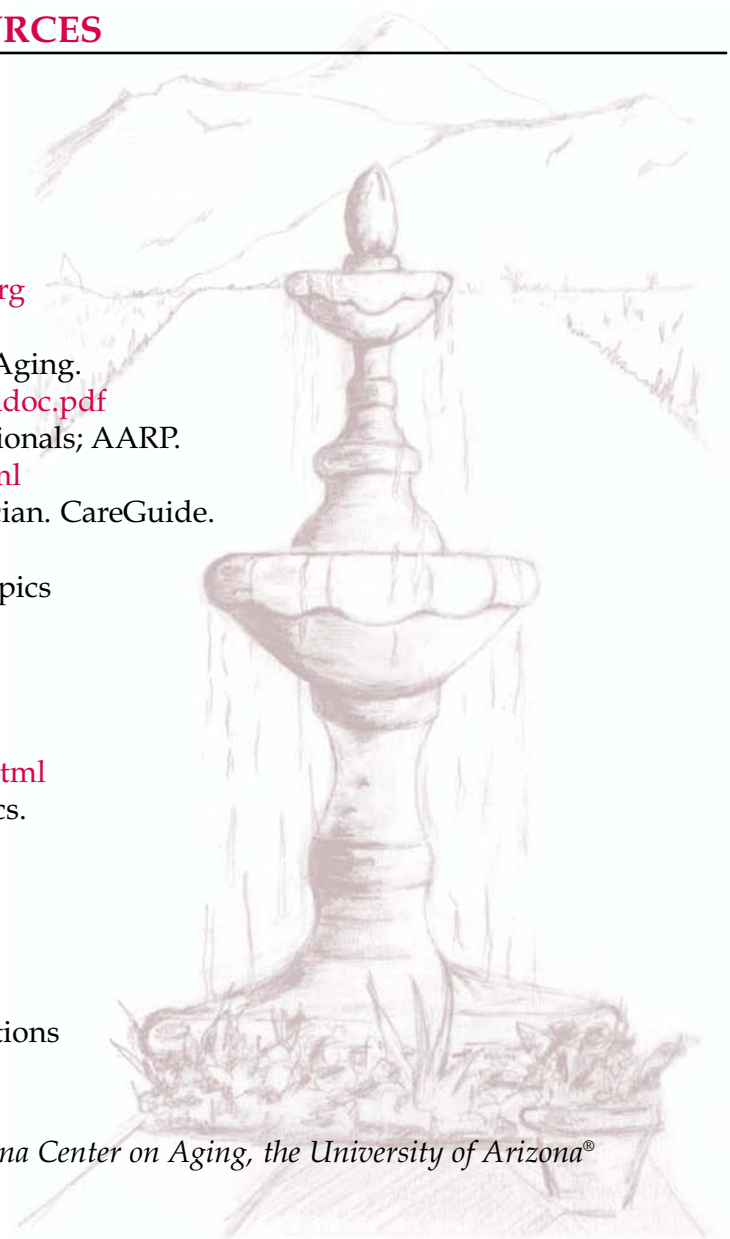
- American Board of Medical Specialties, 1007 Church St., Suite 404, Evanston, IL 60201-5913; Phone: (847)491-9091; www.abms.org Click on: Which medical specialist is for you?

### ❖ How can my relative evaluate whether or not the "partnership" with the doctor is working?

Begin by asking your relative this question, "Can you and the doctor communicate with each other?" This is one of the most important aspects of any partnership. Other qualities that are vital in building a positive partnership are: Does the doctor care about your relative, listen carefully to their concerns and explain things clearly and fully? Does the doctor reassure your relative, when appropriate? Does the doctor or doctor's staff return your relative's telephone calls in a timely manner? Do your relative and the doctor work together as a team to plan for your relative's current and future care? Good health is dependent upon good communication especially for obtaining information, services and the best care possible.

## RESOURCES

- Pima Council on Aging
  8467 E. Broadway Blvd.
  Tucson, AZ 85710-4009
  Phone: (520) 790-7262;
  www.pcoa.org
- Caregiver Consortium; www.arizonacaregivers.org
- Talking with Your Doctor:
  A Guide for Older People. National Institute on Aging.
  www.nia.nih.gov/health/pubs/talking/talkwithdoc.pdf
- Caregiving: Communicating with Health Professionals; AARP.
  www.aarp.org/confacts/caregive/healthprof.html
- Communicating with Your Aging Parent's Physician. CareGuide.
  www.coordinatedcare.com/Careguide/index.jsp
  Click on: Care for Caregivers; Go to: Featured Topics
- Choosing a Doctor. Age Page.
  www.nia.nih.gov/health/agepages/choose.htm
- Communicating with Health Care Professionals.
  Beth Israel Medical Center.
  www.stoppain.org/caregivers/communicating.html
- Frequently Asked Questions About Medical Ethics.
  American Medical Association
  515 N. State St.
  Chicago, IL 60610
  Phone: (312)464-5000;
  www.ama-assn.org
  Click on: Medical Ethics-Frequently Asked Questions



*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# COMMUNICATING WITH PHYSICIANS AND OTHER HEALTH PROFESSIONALS

*helping older relatives or friends to become active participants in their own health care*

In your caregiver role it is important to support and encourage your relative to effectively communicate with treating physicians and other health professionals. Always respect how much your relative is willing to share with you about their health condition.

## BARRIERS TO GOOD COMMUNICATION

Common communication barriers between older patients and physicians include:

- Older persons are less likely to ask questions and more likely to "follow doctor's orders" even if they don't totally understand the purpose of treatments or tests recommended or the medications prescribed.
- Effective communication takes time and insurance companies rarely pay for as much time with the doctor as older patients may want and need.
- Sometimes when a caregiver is present at a medical visit, the doctor or doctor's staff may be inclined to speak solely to the caregiver and not the older person. This may make the older person feel invisible and powerless over decisions about their own health care.
- Attitudes about "aging" may also prevent successful communication. Physical problems affect persons of any age. Both your relative and the health professional should believe that ill health is not something to expect as part of growing older.

## CREATING A PARTNERSHIP

Speak to your relative about viewing the relationship with the physician as a "partnership" where both partners must share information to achieve the best possible care. Being a good partner means to:

- Take good care of yourself
- Practice medical self-care at home
- At the first sign of a health problem write down the symptoms
- Play an active role in the medical visit by asking questions, stating your preferences for care and taking responsibility for your own health. This includes asking questions if the doctor's explanations or instructions are unclear, bringing up problems even if the doctor doesn't ask and letting the doctor know if a treatment isn't working. Many older persons bring a tape recorder to medical visits to make sure they can correctly recall what was said.
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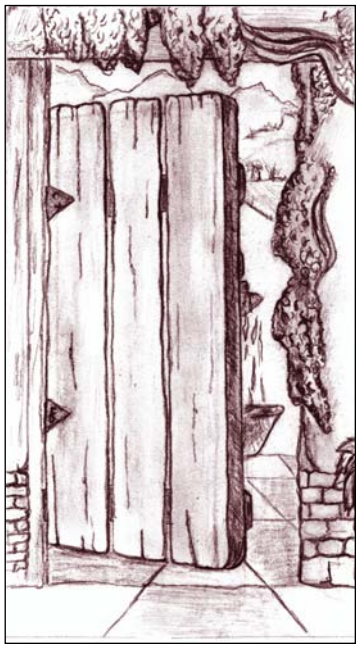

## SHARING INFORMATION

Before the visit, you may want to discuss with your relative the following tips about sharing information:

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## PHYSICIAN BACKGROUND

Your relative may want to know about a physician's training and experience including whether or not the doctor is Board Certified and in what field. Doctors who are Board Certified have had additional training specializing in a certain field/area of medicine. Board Certification is one way for your relative to tell about a doctor's expertise but it does not guarantee availability when needed nor does it measure ability to communicate effectively.
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## EVALUATING THE PARTNERSHIP

Begin by asking your relative this question, "Can you and the doctor communicate with each other?" This is one of the most important aspects of any partnership. Other qualities that are vital in building a positive partnership are: Does the doctor care about your relative, listen carefully to their concerns and explain things clearly and fully? Does the doctor reassure your relative, when appropriate? Does the doctor or doctor's staff return your relative's telephone calls in a timely manner? Do your relative and the doctor work together as a team to plan for your relative's current and future care? Good health is dependent upon good communication especially for obtaining information, services and the best care possible.

# COMUNICANDOCE CON DOCTORES Y OTROS PROFECIONALES DE SALUD

*ayudando a parientes y amigos que son ancianos a ser participes activos en su propia salud*

## PREGUNTAS FRECUENTEMENTE PREGUNTADAS ACERCA DE COMO COMUNICARCE CON PROFECIONALES DE SALUD

En su pocision como proveedor de cuidado para su pariente es importate apoyar y motivar a su pariente para que se comunique efectivamente con el doctor y otros profecionales medicos que estan dando el tratamiento. Siempre respete cuanto su pariente esta dispuesto a compartir con usted acerca de su salud.

❖ **Cuales son las mayores barreras para una buena comunicacion entre pacientes de edad y sus doctores?**

Es mas probable que personas de edad no pregunten preguntas al doctor y es mas probable que "siguan las ordenes del doctor" incluso cuando no entienden completamente el propocito del tratamiento o pruebas recomendadas o las medicinas recetadas. Muchas veces pacientes de edad prefieren atenerce a la experiencia del doctor que estar envueltos en el proceso de hacer decisiones. Otra barrera es que comunicacion se toma tiempo y companias de seguros raramente pagan por el tiempo que un paciente de edad desee o necesite pasar con un doctor. Tambien cuando un proveedor de cuidado acompaña a la persona de edad a una visita medica el doctor o los trabajadores del doctor pueden sentirce inclinados a comunicarce solamente con el proveedor de cuidado y no con la persona de edad. Esto puede hacer sentir a la persona de edad como invisible y sin poder sobre decisiones que tienen que ver con su propio cuidado de salud. Aun mas, actitudes acerca de "personas de edad" pueden tambien prevenir conversaciones de exito entre profecionales medicos y personas mayores. Problemas fisicos afectan a personas de cualquier edad, y, despues de todo, una "persona de edad" es solamente una persona que a vivido mas tiempo que una persona mas joven. Para tener una muy buena comunicacion, su pariente y el profecional de salud deberian de creer que una salud enferma no es algo que esperar como parte de ser mas mayor.

❖ **Como puedo ayudar a mi pariente a tomar una parte mas activa en comunicarce con el doctor?**

Hable con su pariente acerca de ver la relacion con su doctor como un "compañerismo" donde los dos compañeros tienen que compartir informacion para poder obtener el mayor cuidado que sea posible. Ser un buen compañero significa lo siguiente: Cuidarce a si mismo; practicar su propio cuidado medico en su hogar; a la primera señal de un problema medico escriba los simptomas; sea activo/a en su participacion con el doctor haciendo preguntas y diciendo sus preferencias para cuidado y tomando responsabilidad por su propia salud. Esto incluye asiendo preguntas si las explicaciones del doctor o instrucciones no son claras, mencionado problemas aunque el doctor no pregunte y diciendole al doctor si un tratamiento no esta funcionando. Puede alludar a su pariente a hacer una lista de preguntas y preocupaciones. Muchas personas de edad traen una maquina para grabar sus visitas con el medico para estar seguros de recordar correctamente lo que fue dicho. Sugiera a su pariente preguntar las siguientes preguntas a su doctor: Que enfermedad tengo? Cuales son mis opciones para tratamiento (medicinas o tratamientos aleternativos)? Que debo esperar me pase con o sin tratamiento? Mi seguro de salud cubrira todos los gastos de mi tratamiento? Existe informacion escrita acerca de mi enfermedad, tratamientos sugeridos y medicamentos? Cual es la major manera de contactar al doctor (telefono, e-mail, etc.)? Si el doctor receta un medicamento, sugiera que su pariente pregunte lo siguiente: Cual es el nombre de la medicina? Existe una forma generica de la medicina recetada? Cuantas veces y por cuanto tiempo es que la medicina debe ser tomada? Que puede pasar si la medicina no se toma como fue recetada? Que comidas, otros medicamentos, o actividades deben ser prevenidas mientras tomando esta medicina? Cuales son posibles efectos secundarios en tomar este medicamento como fue recentado ( soñoliento, constipacion, etc)?

## ❖ Existen sujerencias que puedan ayudar a preparar a mi pariente para una visita medica?

Antes de la visita, puede hablar con su pariente y compartir las siguientes sugerencias acerca de compartir informacion.

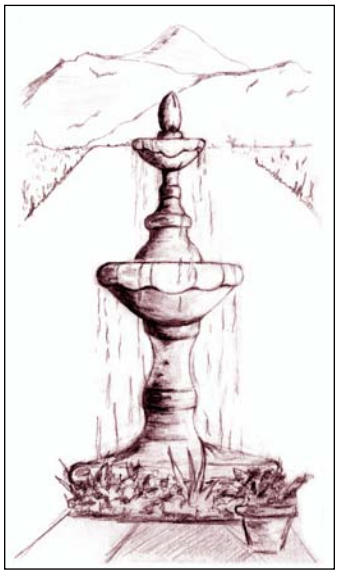
- Sea honesto- Es muy importante ser tan honesto como sea possible acerca de lo que le esta pasando tanto emocionalmente como fisicamente. Sugiera que su pariente no mensione cosas que piense el doctor quiere escuchar; por ejemplo, que el/ella hace ejercisio regularmente y come menos comidas grasosas. Aunque este tipo de respuestas pueden ser naturales, no es en el major interes de su pariente. El doctor puede proveer el mayor tratamiento solo cuando sabe que es lo que realmente esta sucediendo.
- Manteniendoce en el punto- Rutinariamente cada paciente esta citado para un cierto tiempo. Su pariente puede hacer el major uso del tiempo al darle al doctor su mayor descripcion de los simptomas, cuando empezaron, cada cuando pasa, y si se enta mejorando o empeorando. Este seguro que su pariente alla pedido suficiente tiempo para comunicar su condicion y preocupaciones. Cuando confirmando la cita es necesario que su pariente mensione que mas tiempo del que normalmente dura la visita sera necesario. Su pariente no deberia irse asta que se tenga un claro entendimiento del diagnostico, tratamiento, y lo que sera necesario para recuperarse y matenerce en buena salud.
- Preguntar acerca de opciones y tratamientos convencionales- Muchas condiciones, sino muy serias pueden ser tratadas sin medicamentos. Su doctor puede sugerir que su pariente trate hacer ejercicio, buena nutricion, metodos para reducir el estres, suplementos herbales y vitaminas a si como otros metodos de terapias para aliviar los simptomas.
- Aprendiendo mas acerca de pruebas medicas y otros procedimientos- Su pariente puede necesitar pruebas de sangre, rayos-X o otras pruebas para que el doctor pueda descubrir que es lo que esta mal o aprender mas acerca de la enfermedad y proponer posibles tratamientos. Sugiera a su pariente que pregunte al doctor porque la prueba es importante, que sera el costo y como prepararse para la prueba (no comer o tomar medicamentos por un periodo de tiempo antes de la prueba). Su pariente talvez desee pedir informacion escrita que describa la prueba o procedimiento. Recuerdele a su pariente preguntar cuando esperar (y como obtener) los resultados de las pruebas, y si el doctor estara disponible para responder a cual quier pregunta que resulte, y si una visita al doctor sera necesaria. Su pariente puede pedir los resultados de las pruebas en forma escrita. Si las pruebas son echas por un especialista, su pariente deberia de pedir que los resultados sean mandados al doctor primordial.
- Preguntandole al doctor acerca del diagnostico y que esperar-Su pariente deberia de preguntar al doctor las siguientes preguntas: Que podria haber causado la condicion? La condicion sera permanente? Que tratamiento es mayor para la condicion? Cuales seran los efectos de largo termino en mi vida? Como puedo aprender mas acerca de mi enfermedad/condicion?
- Entendiendo lo que el doctor le ha dicho- Si su pariente no entiende algo, entonces pida al doctor que lo explique otra vez. Al repetir lo que fue dicho le ayudara a su pariente estar seguro que lo que escucho fue lo correcto.

## ❖ Como es que mi pariente puede informarce de las credenciales del doctor?

Su pariente talvez desee saber acerca de las credenciales y experiencia del doctor incluyendo si el doctor es Certificado por el Concilio de Medicina y en cual campo. Doctores que son certificados por el Concilio de Medicina han tenido entrenamiento adicional en su especialidad en un cierto campo/ area de medicina. Certificacion por el Concilio de Medicina es una manera en la cual su pariente puede darce cuenta de la experiencia del doctor, pero no garantiza abilidad cuando se necesite o abilidad para comunicarce efectivamente.

Para informacion acerca de las credenciales del doctor, educacion o entrenamiento, historia diciplinaria y mala practica/ criminalizacion contacte:

- El Concilio Medico de Arizona, 9545 E. Doubletree Ranch Rd, Scottsdale, AZ 85258-5539; Telefono: (480) 551-2700; o llame totalmente gratis a (877) 255-2212; www.bomex.org Oprima en: AZDOCInfo: Doctores, Recidente y Asistente de Doctores (PA) Busqueda



- La Sociedad del Condado de Pima para Doctores, 5199 E. Farness Dr., Tucson, AZ 85712; Telefono: (520) 795-7985; www.pimamedicalsociety.org

Para informacion acerca de Especialistas Medicos certificados por el Concilio de Medicina incluyendo una descripcion de la especialidad del medico, las credenciales del especialista medico, educacion y entrenamiento, tambien para acceso a un directorio de todos los especialistas, llame a:

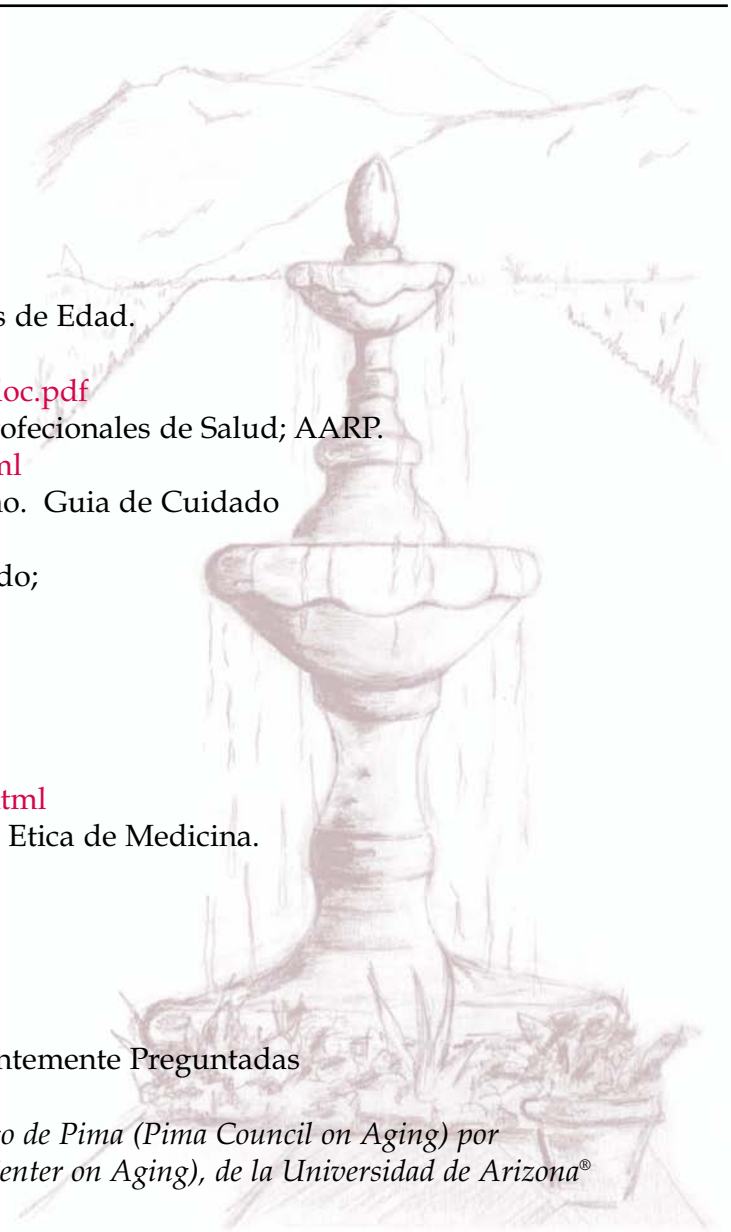
- Asociacion de Medicos Especialistas, 1007 Church St., Suite 404, Evanson, IL 60201-5913; Telefono: (847491-9091;www.abms.org Oprima en: Cual especialista es para usted?

### ❖ Como puede mi pariente evaluar si el "compañerismo" con su doctor esta funcionando?

Empieze preguntandole a su pariente esta pregunta, "El doctor y usted pueden comunicarce?" Este es uno de los mas importantes puntos de cualquier compañerismo. Otras cualidades que son vitals en establecer un compañerismo positivo son: El doctor le importa su pariente, escucha cuidadosamente a su pariente y le explica las cosas claramente y completamente? Su doctor ase sentir a su pariente seguro/a, cuando es apropriado? El doctor o los trabajadores del doctor le regresan las llamadas de una menera efectiva? Su pariente y el doctor trabajan como equipo para planear el cuidado de su pariente ahora y en el futuro? Buena salud depende en una buena comunicacion especialmente para obtener informacion, servicios y el major cuidado posible.

## RECURSOS

- El Concilio de Pima para Ancianos
  8467 E. Broadway Blvd.
  Tucson, AZ 85710-4009
  Telefono: (520) 790-7262;
  www.pcoa.org
- Acuerdo para Proveedores de Cuidado;
  www. Arizonacaregivers.org
- Hablando con su doctor: Una Guia para Personas de Edad.
  Instituto Nacional para Ancianos
  www.nia.nih.gov/healthpubs/talking/talkwithdoc.pdf
- Proveedores de Cuidado: Comunicandose con Profecionales de Salud; AARP.
  www.aarp.org/confacts/caregive/healthprof.html
- Comunicandose con el doctor de su Padre anciano. Guia de Cuidado
  www.coordinatedcare.com.Caregive/index.jsp
  Oprima en: Cuidado para proveedores de Cuidado;
  Vaya a: Temas Corrientes
- Escojiendo un doctor: Pagina de edad.
  www.nia.nih.gov/health/agepages/choose.htm
- Comunicandoce con Profecionales de Salud.
  Centro Medico Beth Israel
  www.stoppain.org/caregivers/communicating.html
- Preguntas frecuentamente preguntadas acerca de Etica de Medicina.
  Asociacion Americana de Medicos
  515 N. State St.
  Chicago, IL 60610
  Telefono: (312 464-5000;
  www.ama-assn.org
  Oprima en: Etica de Medicina- Preguntas Frecuentemente Preguntadas



*Preparado para el Concilio de Envejecimiento de Pima (Pima Council on Aging) por el Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

# END OF LIFE DECISIONS

*helping older relatives or friends make more informed choices about end of life decisions*

## FREQUENTLY ASKED QUESTIONS ABOUT HOSPICE CARE

At the end of a life limiting illness there may come a time when the person chooses to stop aggressive treatment efforts to change the course of the disease and seek comfort care. In your role as a caregiver, this may be an appropriate time to discuss the option of hospice care with your loved one.

### ❖ What is Hospice and Palliative Care?

Originating in the medieval ages, the term hospice meant lodging for travelers that provides comfort and security. The modern hospice approach to care focuses on comfort and dignity for the dying patient and their loved ones. Each patient is cared for in a manner that allows that person to die as they have lived, in harmony with his or her lifestyle. The focus is on caring, not curing. This approach is called palliative care and aims for pain relief and symptom control rather than cure. This philosophy is at the heart of hospice care and is shared by the program's highly trained staff. Hospice patients are cared for by a team of physicians, nurses, social workers, counselors, hospice certified nursing assistants, clergy, therapists and volunteers. Hospice care is available to anyone regardless of age or type of illness.
The basic principles of Hospice care are:

- Death with dignity. End-of-life care that eases both physical and emotional pain.
- Palliative care. To achieve the best quality of life through relief of suffering and control of symptoms.
- Individual control over life. Care that respects the choices of the dying and involves the patient in all aspects of their care.
- Significance of time. To learn to use time wisely to do what matters most.
- Elimination of isolation for the patient, family and friends. To work together to support the dying person.
- Importance of family. Family and friends are fundamental to the well-being of the patient and should be involved in all aspects of their care.

### ❖ Does hospice provide any services for the family of the dying patient?

Hospice understands that those who are close to a dying person experience the dual pains of shared suffering and of anticipated loss. The entire family is considered to be the patient unit and care is provided to all members as needed. Hospice provides continuing support for caregivers for at least one year following the death of a loved one and sponsors bereavement groups and grief support groups.

### ❖ What kind of services does hospice provide?

The program provides: medical and nursing care, medical equipment and supplies, medication therapy for pain and symptom control, home health aide and homemaker services, social work services, physical, occupational and speech therapies, counseling, respite care, religious support and the coordination of all services needed by the patient and family. Respect for the individual's ethnicity, cultural beliefs, social and sexual preferences are reflected in the services and program of hospice care.

### ❖ Can my loved one remain at home and receive hospice care?

All efforts are made to allow the person the comfort of dying at home. The hospice care team delivers services to the majority of patients in their personal residences. However, hospice care can also be provided in a freestanding hospice building, hospital or nursing home.

### ❖ Is the cost of hospice care covered by insurance?

Hospice coverage is widely available and is covered by Medicare, Medicaid (ALTCS) and by most private insurance providers. To be sure of coverage, the person should check with their employer, health insurance provider, or ALTCS/AHCCCS. Most hospices will provide care for anyone who cannot pay using money raised from the community, memorials and/or foundations.

### ❖ If my relative is covered by Medicare, will there be any additional expenses to be paid?

Medicare covers all services and supplies for the hospice patient related to the terminal illness. Some hospices may require the patient to pay a small co-payment for medications and for respite care. The person should find out about co-payment when selecting a hospice.

### ❖ How do I know if my loved one is eligible for hospice care?

It is required that a patient entering hospice care have an attending physician. Most physicians know about hospice care. The patient and family should feel free to discuss hospice with their physician at anytime during a life limiting illness. Other criteria for acceptance into hospice include:

- The patient must have a diagnosis of a terminal illness.
- The disease is beyond the state of aggressive treatment for cure, and the general life expectancy is less than six months (some hospice programs accept persons with a life expectancy of less than one year).
- Both the patient and family wish to enter the hospice program.
- The physician agrees to the referral and will continue to attend to the patient.
- A competent caregiver is available to the patient in the home if homecare is recommended.

At the end of a loved one's life, while caregivers may feel pain and sadness, they have the opportunity to grow stronger and more courageous with the support provided by a caring hospice program. Hospice is not about death, but the quality of life as it nears its end, for all concerned - the patient, their family and friends.

**Poem: *Twilight***

The quietness of the hour
And colored sky
Bring thoughts which may be likened
To the faint aroma of the wildest flower.

Who has not seen the beauty thus exposed
In this most hallowed hour
Will never know
The eternal magic of the day.

*Husband of a Hospice patient*

**Poem: *Untitled***

Moment to moment my heart did cry
The ache so deep in our knowing
And now moment to moment that heart
Lessens, with so much togetherness and
Understanding.

*Daughter of a Hospice Patient*

## RESOURCES

- Hospice Net. www.hospicenet.org
- Hospice Association of America. www.hospice-america.org
- Last Acts. www.lastacts.org
- Completing a Life Resource Guide.
  www.completingalife.msu.edu
- Growth House (Web clearinghouse on death and dying).
  www.growthhouse.org
- National Hospice Foundation
  1700 Diagonal Road, Suite 625
  Alexandria, VA, 22314
  Phone: (703) 516-4928
  www.hospiceinfo.org
- National Hospice and Palliative Care Organization.
  www.nhpco.org
- Pima Council on Aging
  8467 E. Broadway Blvd.
  Tucson, Arizona 85710-4009
  Phone: (520) 790-7262
  www.pcoa.org
- Robert Wood Johnson End-of-Life Web Directory.
  www.rwjf.org/resourceCenter/
- National Hospice Helpline.
  1-800-658-8898
- Caregiver Consortium.
  www.arizonacaregivers.org

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# END OF LIFE DECISIONS: HOSPICE CARE

*helping older relatives or friends make more informed choices about end of life decisions*

At the end of a life limiting illness there may come a time when the person chooses to stop aggressive treatment efforts to change the course of the disease and seek comfort care. In your role as a caregiver, this may be an appropriate time to discuss the option of hospice care with your loved one.

## HOSPICE AND PALLIATIVE CARE

Originating in the medieval ages, the term hospice meant lodging for travelers that provides comfort and security. The modern hospice approach to care focuses on comfort and dignity for the dying person and their loved ones. Each patient is cared for in a manner that allows that person to die as they have lived, in harmony with his or her lifestyle. The focus is on caring, not curing. This approach is called palliative care and aims for pain relief and symptom control rather than cure. This philosophy is at the heart of hospice care and is shared by the program's highly trained staff. Hospice patients are cared for by a team of physicians, nurses, social workers, counselors, hospice certified nursing assistants, clergy, therapists and volunteers. Hospice care is available to anyone regardless of age or type of illness.

## BASIC PRINCIPLES OF HOSPICE CARE

- Death with dignity. End-of-life care that eases both physical and emotional pain.
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## SERVICES FOR FAMILY

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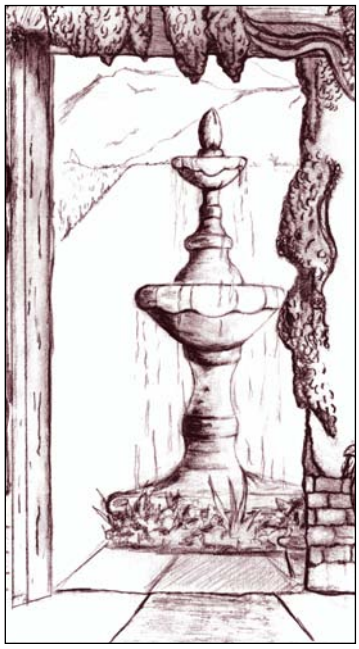

## COMFORT OF HOME

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## ELIGIBILITY CRITERIA

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# DECISIONES DE FIN DE VIDA

*Ayudando a parientes o amistades envejecidos hacer mejor selecciones informativas sobre las decisiones de fin de vida*

## PREGUNTAS QUE SURGEN PREGUNTAR FRECUENTEMENTE SOBRE "HOSPICE CARE" (el cuídado de pacientes con enfermedades terminales)

Al fin de una enfermedad o condición limitando la vida, puede llegar el tiempo cuándo la persona escoja terminar con los tratamientos de esfuerzo agresivos para cambiar el curso de la enfermedad y procurar un cuídado confortable. En sus papel como cuídador, éste será el tiempo apropiado para discutir con su ser querido la opción que el cuídado de un "Hospice" le pueda ofrecer.

### ❖ ¿Qué es "Hospice" y Cuídado Paliativo?

El origin del termino "Hospice" es de los siglos medieval significando el alojamiento de viajeros que se les ofrecen confort y seguridad. La dirección que "Hospice" toma hacia el cuídado enfoca la comodidad y la dignidad de un paciente por morir y la de sus seres queridos. El cuídado de cada paciente es de una manera que permite que muera así como vivio, en armonía con su estilo de vivir. El enfocamiento siempre es en cuídar, no curar. Este enfocamiento se llama cuídado paliativo y su intención es de aliviar el dolor y controlar los sintomas en lugar de curar. Esta filosofía está en el corazón del cuídado en un "Hospice" y se comparte por todo el personal quienes estan muy bien entrenados en éste programa. Los pacientes en "Hospice" son atendidos por un equipo de médicos, enfermeras, trabajadores de seguro social, consejeros, asistentes de enfermería con certificación en "Hospice," sacerdotes, terapeutas y voluntarios. El cuídado de "Hospice" está disponible a toda persona sin limitación de edad o tipo de enfermedad. Los principios basicos del cuídado de un "Hospice" son:

- La muerte con dignidad. El cuídado de fin-de-vida que alivia el dolor físico y emocional.
- Cuídado paliativo. Adquirir la mejor calidad de vida por medio de alivio de sufrimiento y control de sintomas.
- El control de su propia vida individual. La clase de cuídado que respeta las selecciones de la persona por morir y solicita la participación del paciente en todos los aspectos de su cuídado.
- El significativo del tiempo. Aprender usar el tiempo con prudencia para hacer lo qué importa más.
- Eliminar el aislamiento. Trabajar para apoyar a la persona por morir y ver a la persona en si y no la enfermedad.
- La importancia de familia. La familia y los amigos son fundamental para el bienestar del paciente y deben ser procurados en todo el aspecto del cuídado.

### ❖ ¿Ofrece "Hospice" servicios a la familia del paciente por morir?

"Hospice" entiende que aquellas personas cercas del paciente por morir experiensan el dolor mutuo de sufrimiento del paciente y también el dolor de anticipación por la perdida. La familia completa es considerada como un paciente unitario y el cuídado se le ofrece a todos los miembros como se necesite. "Hospice" continua ofreciendo su apoyo al cuídador por lo menos un año despues de la muerte de su ser querido y patrocina grupos de aflicción/pena y grupos para el apoyo de sufrimiento.

### ❖ ¿Qué clase de servicios ofrece "Hospice?"

El programa ofrece cuídado médico y de enfermería, equipo médico y sus provisiones, terapia médica para el dolor y control de sintomas, ayudante de salud en casa y servicios de quehaceres en el hogar, servicios de trabajador social, terapias físicas, de oficio y de articulación, consejeros, cuídado de reposo ("respite care"), apoyo religioso y coordinación de todos los servicios que el paciente y su familia necesite. Los servicios y programas de cuídado que "Hospice" ofrece reflejan el respeto que se tiene hacia la étnica del paciente, sus creencias culturales y preferencias sociales y sexuales.

### ❖ ¿Puede mi ser querido permanecer en casa y recibir el cuídado de "Hospice?"

Se hace todo el esfuerzo de permitir a la persona que muera en la comodidad de su hogar. La mayoría de pacientes que reciben los servicios de cuídado del equipo "Hospice" permanecen en sus residencias personales. Aunque estos servicios de cuídado de "Hospice" también se ofrecen en hospitales, clinicas de reposo (nursing homes), y en instalaciones solas de "Hospice."

### ❖ ¿Cubren los seguros los cobros de cuídado "Hospice?"

La cobertura de cuídado "Hospice" es muy común y está abarcado por "Medicare," "Medicaid(ALTCS)," y por muchos seguros privados. La persona debe comprobar con su patron, sitio de empleo, su proveedor de seguro de salud o con ALTCS/AHCCCS para asegurar que éste tipo de cuídado sea parte de su cobertura. La mayoría de "Hospices" ofrecen cuídado a todas las personas aunque no puedan pagar. En estos casos, los "Hospices" utilizan fondos recaudados de la comunidad, memoriales y/o organizaciones.

### ❖ ¿Si "Medicare" abarca los cobros para mi pariente, habrá otros cobros adicionales que se deben pagar?

"Medicare" paga todos los servicios y materiales en relación a la enfermedad terminal para el paciente de "Hospice." Algunos "Hospices" pueden requerir que el paciente pague un pago minimo por los medicamentos y por el cuídado de reposo ("respite care"). La persona debe preguntar sobre ésto antes de escoger un "Hospice."

### ❖ ¿Como puedo saber si mi ser querido está elegible para el cuídado "Hospice?"

Se requiere que el paciente sea enviado solo con la recomendación de su médico. La mayoría de médicos saben de los servicios de "Hospice." El paciente y su familia deben sentirse seguros de poder discutir a cualquier tiempo el tema de "Hospice" con su médico durante una enfermedad limitando la vida. Otra criteria de aceptación a un "Hospice" incluye:

- El diagnóstico del paciente debe ser de una enfermedad terminal.
- La enfermedad está en el estado avanzado fuera del alcance de un tratamiento agresivo de cura y la vida expectativa en general es menos de seis meses.
- El paciente y su familia desean entrar al programa "Hospice."
- El médico consiente la recomendación y podrá continuar atendiendo al paciente.
- Un cuídador competente debe estar disponible para el paciente en su hogar si se recomienda cuídado en casa.

Aunque los cuídadores sientan dolor y tristeza al fin de la vida de su ser querido, ellos tienen la oportunidad de hacerse más fuertes y valientes con el apoyo que ofrece un programa de cuídado "Hospice." En "Hospice," no se trata de muerte si no de la calidad de vida cúando se acerca la muerte para todos que se preocupan – el paciente, su familia y amistades.

**Poema:** ***Crepúsculo***

La quietud de la hora
Y el cielo de color
Trae pensamientos que pueden asimilar
La aroma tenua de la flor más salvaje.

Quién no ha visto la belleza ya expuesta
En esta hora tan santa
Nunca sabrá
La magia eterna del día.

*Esposo de un paciente de "Hospice"*

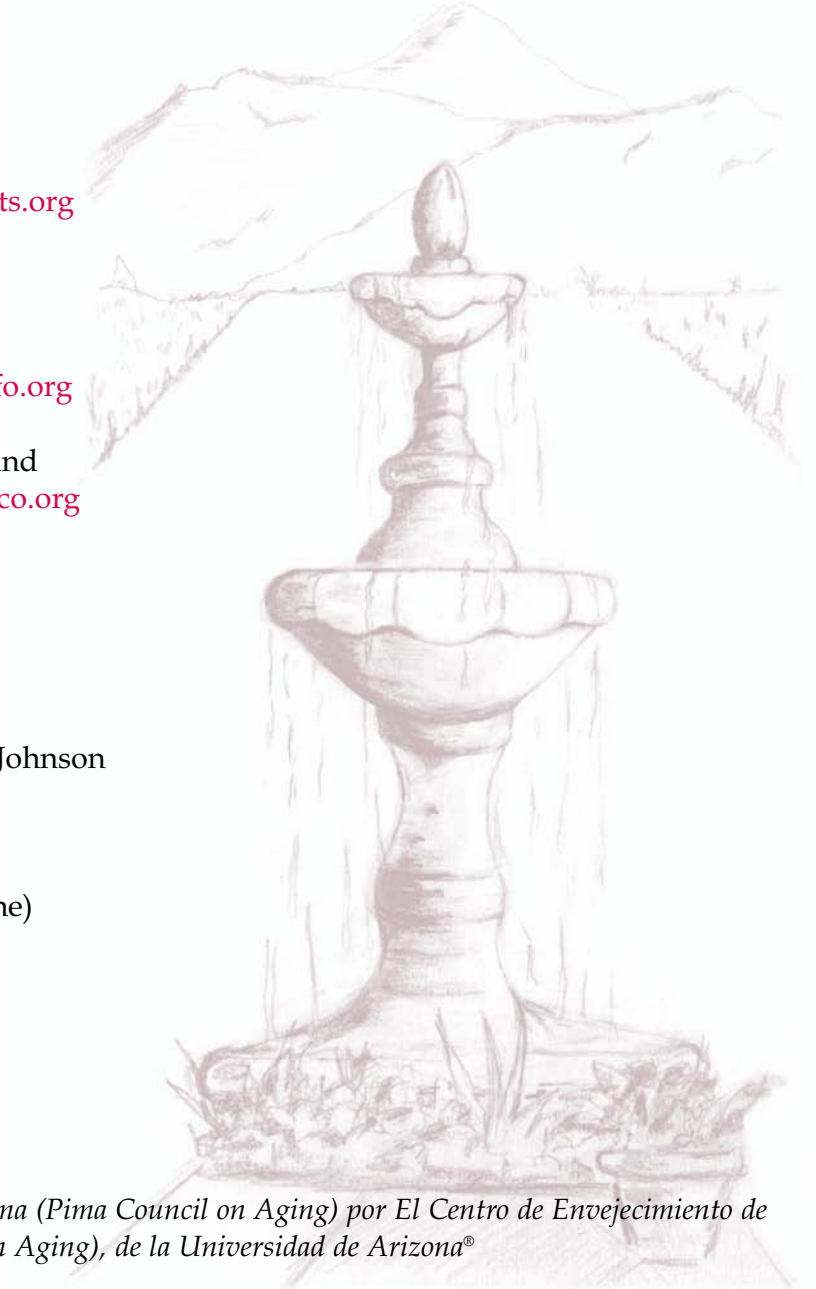
**Poema:**

De momento a momento
mi corazón sí lloro
El dolor tan profundo
En nuestro conocimiento
Y ahora
momento a momento
Ese corazón se empequeña
Con tanta union
Y entendimiento.

*Autor:*
*Hija de un paciente de "Hospice"*

## RECURSOS:

- Hospice Net. www.hospicenet.org
- La Asociación de "Hospice" de America (Hospice Association of America). www.hospice-america.org
- Ultimos actos ("Last Acts"). www.lastacts.org
- La Fundación Nacional de "Hospice," (National Hospice Foundation) 1700 Diagonal Road, Suite 625 Alexandria, VA, 22314 Teléfono: (703)516-4928: www.hospiceinfo.org
- La Organización Nacional de "Hospice" y Cuídado Paliativo (National Hospice and Palliative Care Organization): www.nhpco.org
- El Concilio de Envejecimiento de Pima (Pima Council on Aging) 8467 E. Broadway Blvd. Tucson, Arizona 85710-4009 Teléfono (520)790-7262; www.pcoa.org
- El Directorio Electrónico de Fin-De-Vida de Robert Wood Johnson (Robert Wood Johnson End-of-Life Web Directory). www.rwjf.org/resourceCenter/
- La Linea Telefónica de Ayuda Nacional de "Hospice." (National Hospice Helpline) 1-800-658-8898
- El Consorcio de Cuídadores (Caregiver Consortium). www.arizonacaregivers.org



*Preparado para El Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

# DECISIONES DE FIN DE VIDA: CUIDADO "HOSPICE"

*Ayudando a parientes o amistades envejecidos hacer mejor selecciones informativas sobre las decisiones de fin de vida*

Al fin de una enfermedad o condición limitando la vida, puede llegar el tiempo cuándo la persona escoja terminar con los tratamientos de esfuerzo agresivos para cambiar el curso de la enfermedad y procurar el cuídado confortable. En sus papel como cuídador, éste será el tiempo apropiado para discutir con su ser querido la opción que el cuídado de un "Hospice" le pueda ofrecer.

## "HOSPICE" Y EL CUIDADO PALIATIVO

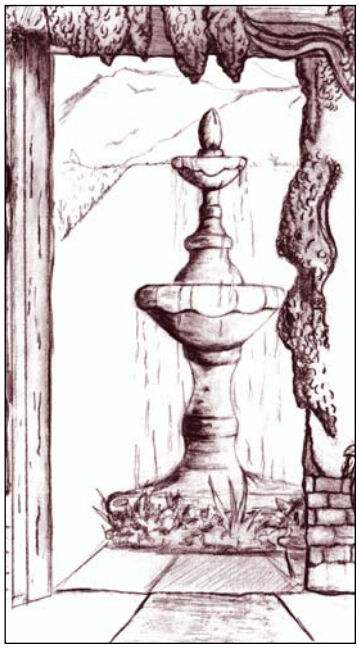
El origin del termino "Hospice" es de los siglos medieval significando el alojamiento de viajeros que se les ofrecen confort y seguridad. La dirección que "Hospice" toma hacia el cuídado enfoca la comodidad y la dignidad de un paciente por morir y la de sus seres queridos. El cuídado de cada paciente es de una manera que permite que muera así como vivio, en armonía con su estilo de vivir. El enfocamiento siempre es en cuídar, no curar. Este enfocamiento se llama cuídado paliativo y su intención es de aliviar el dolor y controlar los sintomas en lugar de curar. Esta filosofía está en el corazón del cuídado en un "Hospice" y se comparte por todo el personal quienes estan muy bien entrenados en éste programa. Los pacientes en "Hospice" son atendidos por un equipo de médicos, enfermeras, trabajadores de seguro social, consejeros, asistentes de enfermería con certificación en "Hospice," sacerdotes, terapeutas y voluntarios. El cuídado de "Hospice" está disponible a toda persona sin limitación de edad o tipo de enfermedad.

## PRINCIPIOS BASICOS DE CUIDADO "HOSPICE"

- La muerte con dignidad. El cuídado de fin-de-vida que alivia el dolor físico y emocional.
- Cuídado paliativo. Adquirir la mejor calidad de vida por medio de alivio de sufrimiento y control de sintomas.
- El control de su propia vida individual. La clase de cuídado que respeta las selecciones de la persona por morir y solicita la participación del paciente en todos los aspectos de su cuídado.
- El significativo del tiempo. Aprender usar el tiempo con prudencia para hacer lo qué importa más.
- Eliminar el aislamiento. Trabajar para apoyar a la persona por morir y ver a la persona en si y no la enfermedad.
- La importancia de familia. La familia y los amigos son fundamental para el bienestar del paciente y deben ser procurados en todo el aspecto del cuídado.

## SERVICIOS PARA LA FAMILIA

"Hospice" entiende que aquellas personas cercas del paciente por morir experiensan el dolor mutuo de sufrimiento del paciente y también el dolor de anticipación por la perdida. La familia completa es considerada como un paciente unitario y el cuídado se le ofrece a todos los miembros como se necesite. "Hospice" continua ofreciendo su apoyo al cuídador por lo menos un año despues de la muerte de su ser querido y patrocina grupos de aflicción/pena y grupos para el apoyo de sufrimiento.



## SERVICIOS DE "HOSPICE"

El programa ofrece cuídado médico y de enfermería, equipo médico y sus provisiones, terapia médica para el dolor y control de sintomas, ayudante de salud en casa y servicios de quehaceres en el hogar, servicios de trabajador social, terapias físicas, de oficio y de articulación, consejeros, cuídado de reposo ("respite care"), apoyo religioso y coordinación de todos los servicios que el paciente y su familia necesite. Los servicios y programas de cuídado que "Hospice" ofrece reflejan el respeto que se tiene sobre la étnica del paciente, sus creencias culturales y sus preferencias sociales y sexuales.

## EL CONFORT DE CASA

Se hace todo el esfuerzo de permitir a la persona que muera en la comodidad de su hogar. La mayoría de pacientes que reciben los servicios de cuídado del equipo "Hospice" permanecen en sus residencias personales. Aunque estos servicios de cuídado de "Hospice" también se ofrecen en hospitales, clinicas de reposo (nursing homes), y en instalaciones solas de "Hospice."

## ABARCAMIENTO DE SEGUROS

La cobertura de cuídado "Hospice" es muy comun y esta abarcado por "Medicare," "Medicaid(ALTCS)," y por muchos seguros privados. La persona debe comprobar con su patron, sitio de empleo, su proveedor de seguro de salud o con ALTCS/AHCCCS para asegurar que éste tipo de cuídado sea parte de su cobertura. La mayoría de "Hospices" ofrecen cuídado a todas las personas aunque no puedan pagar. En estos casos, los "Hospices" utilizan fondos recaudados de la comunidad, memoriales y/o organizaciones.

## ABARCAMIENTO POR "MEDICARE"

"Medicare" paga todos los servicios y materiales en relación a la enfermedad terminal para el paciente de "Hospice." Algunos "Hospices" pueden requerir que el paciente pague un pago minimo por los medicamentos y por el cuídado de reposo ("respite care"). La persona debe preguntar sobre ésto antes de escoger un "Hospice."

## CRITERIO DE ELEGIBILIDAD

Se requiere que el paciente lo esté atendiendo un médico antes de entrar al cuídado "Hospice." La mayoría de médicos saben de los servicios de "Hospice." El paciente y su familia deben sentirse seguros de poder discutir a cualquier tiempo el tema de "Hospice" con su médico durante una enfermedad limitando la vida. Otro criterio de aceptación a un "Hospice" incluye:

- El diagnóstico del paciente debe ser de una enfermedad terminal.
- La enfermedad está en el estado avanzado fuera del alcance de un tratamiento agresivo de cura y la vida expectativa en general es menos de seis meses (algunos programas de "Hospice" aceptan personas con la vida expectativa de menos de un año).
- El paciente y su familia desean entrar al programa "Hospice."
- El médico consiente la recomendación y podrá continuar atendiendo el paciente.
- Un cuídador competente debe estar disponible para el paciente en su hogar si se recomienda cuídado en casa.

Aunque los cuídadores sientan dolor y tristeza al fin de la vida de su ser querido, ellos tienen la oportunidad de hacerse más fuertes y valientes con el apoyo que ofrece un programa de cuídado "Hospice." En "Hospice," no se trata de muerte si no de la calidad de vida cúando se acerca la muerte para todos que se preocupan – el paciente, su familia y amistades.

*Poema: Crepúsculo*
*La quietud de la hora*
*Y el cielo de color*
*Trae pensamientos que pueden asimilar*
*La aroma tenua de la flor más salvaje.*

*Quién no ha visto la belleza ya expuesta*
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*Poema:*
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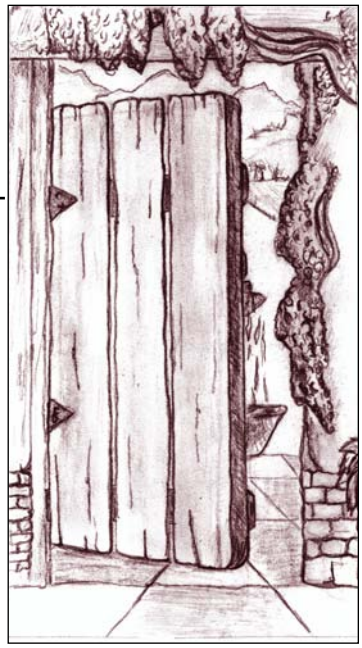
*En nuestro conocimiento*
*Y ahora momento a momento*
*Ese corazón se empequeña*
*Con tanta union*
*Y entendimiento*
*Hija de un paciente de "Hospice"*

# END OF LIFE DECISIONS

*helping older relatives or friends make more informed choices about end of life decisions*



## FREQUENTLY ASKED QUESTIONS ABOUT A DEATH AT HOME

Reaching the end of your caregiver journey is a very emotional time demanding much courage and compassion. You may want to "be there" for your loved one, providing support and making sure their wishes are carried out. Often we do foresee the death of our loved ones as we witness gradual declines in their health and functioning, but sometimes death comes suddenly.

### ❖ How do we begin to prepare for this time?

The caregiver can begin preparing by gathering the facts:

- Learn about the diseases or conditions that affect your relative by talking with the health professionals providing care. Ask about symptoms, changes in health or behavior that may occur and the "normal" course of the disease and/or condition.
- Contact organizations and foundations that have information such as the Alzheimer's Association, Heart Association, Cancer Society and Parkinson's Association. Check the telephone book, library and Pima Council on Aging for listings.
- If your relative has a terminal illness, you may want to become familiar with the services and benefits offered by hospice care. Your relative should feel free to discuss hospice care with their physician at any time during a life limiting illness. The hospice approach to care focuses on comfort and dignity for the dying patient and their loved ones. All efforts are made to allow the person the comfort of dying at home.

Dying is a part of living, but sometimes endings come sooner than expected. Often we avoid the issues surrounding death - not because we do not care, but because we feel so helpless at the time of this final crisis.

### ❖ My family member was sleeping so soundly that she didn't hear me enter her room. For a moment I was frightened that she had died. She was fine, but what should we do if this really happens?

It is frightening to face this situation without the resources you need. Knowing the information and your loved one's preferences will help you manage this difficult time. If your loved one is in the hospital, nursing home, hospice program or other healthcare facility when death occurs, the facility will take care of many details and help with arrangements, such as: declaring the person's time of death, calling designated family members, the physician, and mortuary. If you want to spend time with your loved one, facility staff will often allow family members a few private moments with the deceased. In most cases, the facility's social worker or other trained health professional will be there to help and stay with the family until arrangements are made.

### ❖ What if you don't expect the death and it is not in the hospital or a medical setting?

When someone dies at home, or other home care or non-medical setting, the details are more complicated. If your relative is enrolled in a Hospice program you will be instructed to call the Hospice emergency number instead of 911. Hospice staff are highly trained professionals and will know exactly what to do. Staff will come to the home, assist with details and offer support while you wait.

If your relative is not in a hospice program, and you or another person finds that your loved one has died, it will be necessary to **call 911 immediately** to report the situation. (If a paid caregiver from a health agency is present they may need to call their agency to report the situation as well). After you have called 911 or the hospice team, *you should call a friend or support person to come and stay with you while you wait.*

There will be a number of medical emergency responders that will arrive at the place of death to review the incident. When the 911 team responds, they will notify the appropriate law enforcement personnel (police or sheriff's department). The primary physician of the deceased will be contacted to determine if the death is expected and to inquire whether the physician is willing to sign the death certificate. If the physician indicates that it is an expected event (such as a terminal illness) then arrangements will be made to take the deceased person to the designated mortuary or funeral home.

If the death does not seem reasonable, looks suspicious, or the physician doesn't know their patient well enough to feel comfortable signing the death certificate or cannot be contacted, then the law enforcement team will call the office of the medical examiner. The medical examiner will transport the body to their office to determine the cause of death, which may include an autopsy. The body of the deceased person will not be released until a determination as to cause of death has been made, but this usually only creates a delay of a few days, often less, depending on the circumstances.

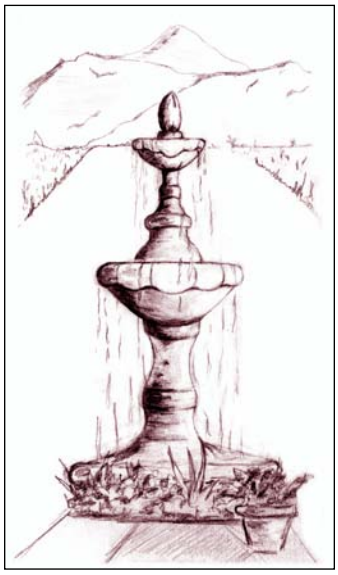
### ❖ Is there always an autopsy?

No, actually the office of the medical examiner often retains the body of a deceased person until a mortuary is designated, and only conducts an investigation or autopsy if there is enough information to indicate a crime may have been committed. They are well trained in cultural and religious differences and make every effort to honor beliefs that object to an autopsy. However when necessary, it is part of the procedure.

### ❖ How long will the whole process take?

The process can be very time consuming, and may span several hours. Losing a loved one is very difficult even when anticipated, and perhaps more so if the death is sudden. It is important that you try to stay calm, and that you not disturb the situation until the 911 team and law enforcement arrives.

Again, it is important that your second call after calling 911 should be to a relative or close friend who is willing to be there and comfort you while waiting for the proceedings to be completed. Be aware that it may take several hours, and that even if you think you are prepared, you will probably be in distress.



### ❖ What about the numbers of people, who will be coming into the home, such as, paramedics, police, and doctors?

Generally, the 911-paramedic team may have two to three members. The law enforcement team may have one or two officers responding, unless you suspect something criminal has occurred, then one or more detectives may also be present. If there seems to be more about the scene that requires investigation or documentation, a number of law enforcement personnel from the Department of Forensics may arrive to take photographs, fingerprints and conduct other investigative procedures. Also present would be the physician or medical examiner, and/or mortuary personnel to transport the body.

❖ **What kind of questions will be asked?**

Primarily, responders will ask questions about your relative's past medical history, medications taken and for what conditions, treatments being administered, as well as the names and contact numbers of treating physicians. They may inquire about your relative's overall well being, how much assistance they needed to conduct daily activities and other routine questions to clarify the circumstances surrounding the death.

## RESOURCES

**For a list of Grief and Support Groups, contact:**

**Pima Council on Aging**
8467 E. Broadway Blvd.
Tucson, Arizona 85710-4009
Phone: (520) 790-7262
www.pcoa.org

**National Hospice Foundation**
1700 Diagonal Road, Suite 625
Alexandria, VA 22314
Phone: (703) 516-4926
www.hospiceinfo.org

**National Hospice Helpline.**
1-800-658-8898

**Grief and Loss Resource Center.**
www.spirit-net.ca/grief/grief.html

**Caregiver Consortium.**
www.arizonacaregivers.org

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# END OF LIFE DECISIONS: A DEATH AT HOME

*helping older relatives or friends make more informed choices about end of life decisions*

Reaching the end of your caregiver journey is a very emotional time demanding much courage and compassion. Often we do foresee the death of our loved ones as we witness gradual declines in their health and functioning, but sometimes death comes suddenly.

## GATHERING INFORMATION

The caregiver can begin preparing for this time by gathering the facts:

- Learn about your relative's diseases or conditions by talking with health professionals. Ask about symptoms, changes in health or behavior that may occur and the "normal" course of the disease and/or condition.
- Contact organizations and foundations that have information about the diseases or conditions affecting your relative. Check the telephone book, library and Pima Council on Aging for listings.
- If your relative has a terminal illness, you may want to become familiar with the services and benefits offered by hospice care. Your relative should feel free to discuss hospice care with their physician at any time during a life limiting illness. The hospice approach to care focuses on offering the terminally ill person the comfort and dignity of dying at home, if at all possible.

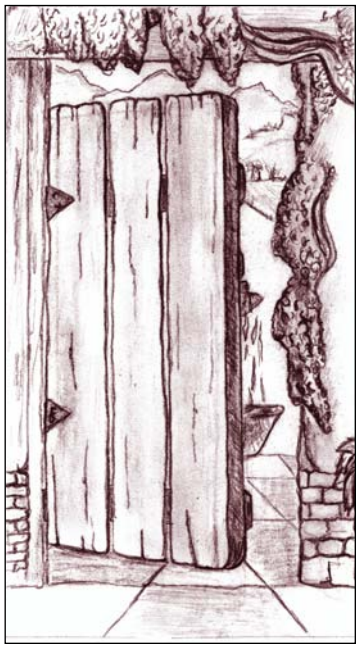
Dying is a part of living. Often we avoid the issues surrounding death - not because we do not care, but because we feel so helpless at the time of this final crisis.

## DEATH AT HOME

When someone dies at home, or other home care or non-medical setting, certain actions must be conducted. If your relative is not in a hospice program, and you or another person finds that your loved one has died, it will be necessary to call 911 immediately to report the situation. If your relative is enrolled in a Hospice program you will be instructed to call the Hospice emergency number instead of 911. Hospice staff will come to the home, assist with details and offer support while you wait.

## RESPONDING PROFESSIONALS

- A number of medical emergency responders will arrive at the place of death to review the incident. When the 911 team responds, they will notify the appropriate law enforcement personnel.
- The primary physician of the deceased will be contacted to determine if the death is expected and to inquire whether the physician is willing to sign the death certificate. If the physician indicates that it is an expected event (such as a terminal illness) then arrangements will be made to take the deceased person to the designated mortuary or funeral home. If the death looks suspicious, or the physician doesn't know their patient well enough to feel comfortable signing the death certificate or cannot be contacted, then the law enforcement team will call the office of the medical examiner.
- The medical examiner will transport the body to their office to determine the cause of death, which may include an autopsy. The body of the deceased person will not be released until a determination as to cause of death has been made, but this usually only creates a delay of a few days, often less, depending on the circumstances.



## TIME CONSUMING PROCESS

This process may span several hours. Losing a loved one is very difficult even when anticipated, and perhaps more so if the death is sudden. It is important that you try to stay calm, and that you not disturb the situation until the 911 team and law enforcement arrives. It is important that you consider calling a relative or close friend who is willing to be there and comfort you while waiting for the proceedings to be completed. Be aware that it may take several hours, and that even if you think you are prepared, you will probably be in distress.

## PRESENCE OF RESPONDERS IN THE HOME

The 911-paramedic team may have two to three members. The law enforcement team may have one or two officers responding, unless you suspect something criminal has occurred, then one or more detectives may also be present. If there seems to be more about the scene that requires investigation or documentation, a number of law enforcement personnel from the Department of Forensics may arrive to take photographs, fingerprints and conduct other investigative procedures. Also present would be the physician or medical examiner, and/or mortuary personnel to transport the body.

## TYPES OF QUESTIONS THAT MAY BE ASKED

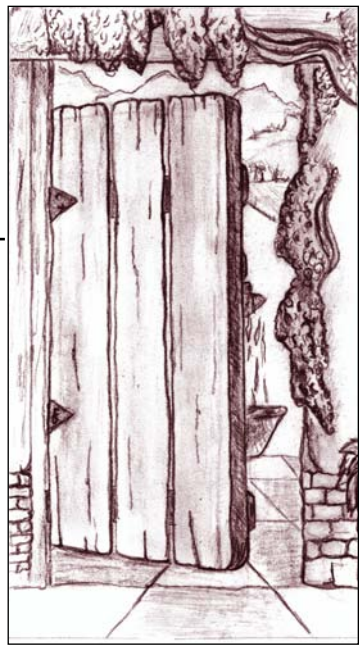
Responders will ask questions about your relative's past medical history, medications taken and for what conditions, treatments being administered, as well as the names and contact numbers of treating physicians. They may inquire about your relative's overall well being, how much assistance they needed to conduct daily activities and other routine questions to clarify the circumstances surrounding the death.

## AUTOPSY

The office of the medical examiner often retains the body of a deceased person until a mortuary is designated, and only conducts an investigation or autopsy if there is enough information to indicate a crime may have been committed. They are well trained in cultural and religious differences and make every effort to honor beliefs that object to an autopsy. However when necessary, it is part of the procedure.

# DECISIONES DE FIN DE VIDA

*Ayudando a parientes o amistades envejecidos hacer mejor selecciones informativas sobre las decisiones de fin de vida*



## PREGUNTAS QUE SURGEN PREGUNTAR FRECUENTEMENTE SOBRE LA DECISION DE MORIR EN CASA

Los tiempos serán muy emotivos y se necesita mucha compasión y valentía cuándo se ve uno alcanzando el fin de su tiempo como cuídador. Tal vez usted querrá "estar ahí" para su ser querido, rindiendo apoyo y asegurando que sus deseos se esten cumpliendo. Frecuentemente la muerte de nuestro ser querido es prevista depues de haber presenciado el decaimiento gradualmente de su salud y funcionamiento pero hay veces que le muerte es inesperada.

### ❖ ¿Cómo debemos comenzar a preparar para este tiempo?

El cuídador puede comenzar con juntar todos los datos:

- Hable con los profesionales de salud que están atendiendo a su pariente y aprenda las enfermedades o condiciones que le afectan. Pregunte de los sintomas, cambios de salud o comportamiento que pueda ocurrir y del curso "normal" de la enfermedad y/o condición.
- Pongase en contacto con las organizaciones y fundaciones que tengan información así como las Asociación de Alzemia (Alzheimer's Association), la Asociación del Corazón (Heart Association), la Sociedad De Cáncer (Cancer Society) y la Asociación de Parkinsons (Parkinsons Association). Revise la guía telefonica, su biblioteca local o comuniquese con el Concilio de Envejecimiento de Pima (Pima Council on Aging) para los números de teléfono que necesite.
- Si su pariente tiene un enfermedad terminal, tal vez quiera usted informarse de los servicios y beneficios que se rinden en un "Hospice" (asilo para pacientes con enfermedades terminales). Su ser querido debe sentirse capaz de discutir a cualquier tiempo y libremente con su médico durante una enfermedad que limite su vida sobre el cuídado que "Hospice" ofrece. Un "Hospice" rinde cuídado enfocando la comodidad y dignidad de el paciente por morir y sus seres queridos. Se hace todo el esfuerzo para que el paciente pueda morir en la comodidad de su hogar.

La muerte es parte de la vida aunque hay veces que esto ocurre de pronto sin advertencia. Muy frecuentemente evitamos los temas a respecto a la muerte - no porque no nos interesa o nos preocupa pero porque nos sentimos indefensos en el tiempo de la crisis final.

### ❖ Mi miembro de familia estaba durmiendo tan profundamente que no me escucho al entrar al cuarto, por un solo momento temí que se había muerto. Ella estaba bien pero, ¿que debemos hacer si esto de veras ocurre?

Esta situación es de veras muy desagradable especialmente cuándo uno se enfrenta a ello sin los recursos necesarios. Estos tiempos tan difíciles pueden ser menos trabajosos si usted ya sabe la información y las preferencias de su ser querido. Si su ser querido está en el hospital, clinica de ancianos, programa para pacientes con enfermedades terminales o otra clase de instalación para el cuídado de salud cuándo ocurra la muerte, la instalación se ocupará de muchos detalles y le ayudará con los arreglos así como: declarando el tiempo de fallecimiento, llamando a los miembros de familia designados, los médicos y la mortuoria. Muchas veces el personal de la instalación permitirá que aquellos miembros de familia que deseen, puedan pasar unos momentos en privacidad con el difunto. En muchos casos, el trabajador social de la instalación o otro profesional de salud entrenado estará ahí para ayudar y se quedará con la familia hasta que todos los arreglos se hayan hecho.

## ❖ ¿Qué si la muerte es inesperada y uno no se encuentra en el hospital o establecimiento médico?

Los detalles surgen ser más complicados cuándo alguien muere en casa o otra parte de cuídado en casa o institución que no sea médica. Si su pariente está registrado con el programa "Hospice" (programa para pacientes con enfermedades terminales), se le dará instrucciones de llamar al teléfono emergente de "Hospice" **en cambio** de marcar "911." El personal de "Hospice" son muy bien entrenados profesionalmente y saben exactamente que hacer. El personal vendrá a la casa, asistirá con los detalles y ofrecerá apoyo mientras que usted espera.

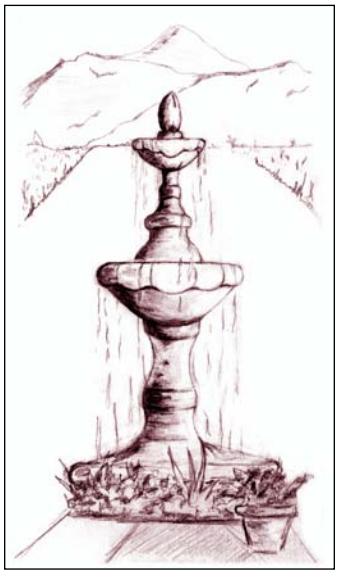
Si su ser querido no está registrado en el programa "Hospice" y usted o alguien se encuentra cuándo su ser querido haya fallecido, será necesario marcar "911" inmediatamente para reportar la situación. (Si está presente el cuídador empleado por la familia de una agencia de salud, puede ser necesario que tenga que reportar la situación a la agencia también.) Es muy importante que despues de haber llamado a "911" o al equipo de "Hospice", **llame a una amistad o persona que venga a su lado para dar apoyo mientras que espera.**

Habrá varias personas del equipo médico emergente que respondan al lugar donde el difunto murio para revisar el incidente. Cuándo el equipo de "911" respondan, ellos notificarán a los oficiales de justicia apropriados (el departamento de policía o sheriff). El médico primario del difunto será notificado para que se determine si la muerte estaba esperada y también para preguntarle si está dispuesto a firmar el certificado de defunción. Si el médico indica que la muerte fue un evento esperado (así como una enfermedad terminal) entonces se harán arreglos para que el difunto sea transladado a una mortuoria o funeraria asignada.

Si la muerte no aparece razonable, se vé sospechosa o el médico no conoce el paciente tan bien como para firmar el certificado de defunción o no puede ser localizado, entonces los oficiales de justicia llamarán a la oficina del médico forense. El médico forense transportará el cuerpo a su oficina para determinar la causa de la muerte que quizás pueda incluír una autopsia. El cuerpo del difunto no se permitirá entregar a la familia hasta que se determine la causa de muerte pero esto no tardará más que unos cuántos días, hay veces menos dependiendo en las circumstancias.

## ❖ ¿Siempre se lleva acabo una autopsia?

No, casi siempre la oficina del médico forense retiene el cuerpo del difunto solo hasta que se nombre una mortuoria y solo conduce una investigación o autopsia cuándo hay bastante información que indique que haya ocurrido un crimen. Ellos están bien entrenados para tomar en cuénta las diferencias de religión y cultura y hacen todo el esfuerzo posible para honrar las creencias que se opongan a una autopsia aunque cuándo es necesario, la autopsia sera parte del procedimiento.



## ❖ ¿Cuánto tiempo dura todo el proceso?

El proceso puede ser muy largo y tal vez dure varias horas. Es muy trabajoso perder un ser querido cuándo esto está anticipado y tal vez aún más cuándo la muerte es inesperada. Es muy importante permanecer calmado(a) y que no altere la situación hasta que el equipo de "911" y los oficiales de policía lleguen.

De nuevo, es muy importante que su segunda llamada despues de "911" sea a un pariente o amistad cercana que esté dispuesto(a) a permanecer con usted y darle apoyo por mientras que espera que terminen todo los procedimientos. Tome en cuenta que esto probablemente tardará varias horas y aunque uno crea que está preparado, es muy posible que esté en el estado de choqué.

❖ **¿Qué tantas personas responderán así como oficiales de policía, médicos y auxiliadores sanitarios?**

En general, el equipo auxiliador sanitario de "911" consiste de dos a tres miembros. El cuerpo de policía a veces tendrá uno o dos oficiales respondiendo, a menos que usted sospeche que un crimen haya ocurrido, entonces se presentarán uno o dos detectives . Si aparece que las circumstancias requierán más investigación o documentación, entonces varios oficiales del departamento forense también estarán presente para tomar fotos, huellas y conducir una investigación más extensiva. También se presentará el médico del difunto o el médico forense y/o el personal de la mortuoria para transportar el cuerpo.

❖ **¿Qué clase de preguntas tendrán?**

Principalmente, el equipo emergente preguntará el historial médico del difunto, los medicamentos qué tomabá y para qué clase de condiciones médicas, qué tipo de tratamiento se sometía y los nombres y números de teléfono de todos los médicos atendiendo al difunto. Le pueden preguntar sobre el bienestar del pariente, qué tanta asistencia necesitaba para conducir sus actividades a diario y otras preguntas de rutina que puedán clarificar las circumstancias alrededor de la muerte.

## RECURSOS

Para una lista de Grupos Dedicados A Dar Apoyo Con La Perdida y La Afflicción (Grief and Support Groups), llame al
**Concilio de Envejecimiento de Pima (Pima Council on Aging),**
8467 E. Broadway Blvd.
Tucson, Arizona 85710-4009
Teléfono (520)790-7262; sitio en el "Internet" www.pcoa.org

**La Fundación Nacional de "Hospice"**
**(National Hospice Foundation)**
1700 Diagonal Road, Suite 625
Alexandria VA 22314
Teléfono (703)516-4928
sitio en el "Internet" www.hospiceinfo.org

**La Linea De Ayuda Nacional De "Hospice"**
(National Hospice Helpline) 1-800-658-8898

**El Centro de Recursos Para La Perdida y La Afflicción**
**(Grief and Loss Resource Center),**
sitio en el "Internet"
www.spirit-net.ca/grief/grief.html

**El Consorcio de Cuídadores (Caregiver Consortium)**
sitio en el "Internet" www.arizonacaregivers.org

*Preparado para El Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

# DECISIONES DE FIN DE VIDA: UNA MUERTE EN CASA

*Ayudando a parientes o amistades envejecidos hacer mejor selecciones informativas sobre las decisiones de fin de vida*

Los tiempos serán muy emotivos y se necesita mucha compasión y valentía cuándo se ve uno alcanzando el fin de su tiempo como cuídador. Tal vez usted querrá "estar ahí" para su ser querido, rindiendo apoyo y asegurando que sus deseos se esten cumpliendo. Frecuentemente la muerte de nuestro ser querido es prevista depues de haber presenciado el decaimiento gradualmente de su salud y funcionamiento pero hay veces que la muerte es inesperada.

## JUNTANDO INFORMACION

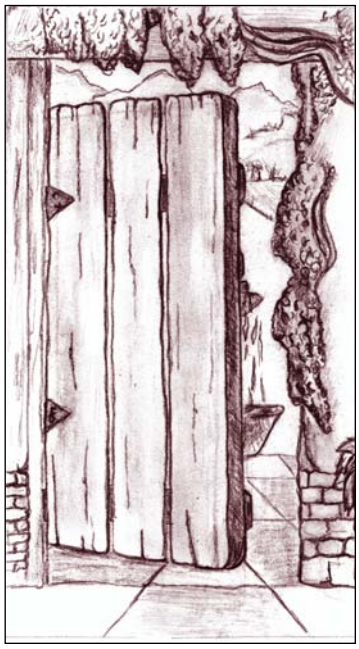
El cuídador puede comenzar con juntar todos los datos:

- Hable con los profesionales de salud que están atendiendo a su pariente y aprenda las enfermedades o condiciones que le afectan. Pregunte de los sintomas, cambios de salud o comportamiento que pueda ocurrir y del curso "normal" de la enfermedad y/o condición.
- Pongase en contacto con las organizaciones y fundaciones que tengan información sobre la enfermedad o condición que le afecta a su pariente. Revise la guía telefónica, su biblioteca local o comuniquese con el Concilio de Envejecimiento de Pima (Pima Council on Aging) para los números de teléfono que necesite.
- Si su pariente tiene un enfermedad terminal, tal vez quiera usted informarse de los servicios y beneficios que se rinden en el cuídado de "Hospice" (programa para pacientes con enfermedades terminales). Su pariente debe sentirse capaz de discutir a cualquier tiempo y libremente con su médico los servicios y beneficios que se ofrecen en un cuídado de "Hospice." Un "Hospice" ofrece cuídado enfocando la comodidad y dignidad del paciente por morir. Se hace todo el esfuerzo para que el paciente permanezca en la comodidad de su hogar al morir.

La muerte es parte de la vida. Muy frecuentemente evitamos los temas a respecto a la muerte - no porque no nos interesa o nos preocupa pero porque nos sentimos indefensos en el tiempo de la crisis final.

## MORIR EN CASA

Cuándo alguien muere en su hogar, o otra clase de cuídado en casa o lugar que no sea médico, ciertas medidas se deben tomar. Si su ser querido no está registrado en el programa "Hospice" y usted o alguien se encuentra cuándo su ser querido haya fallecido, será necesario marcar "911" inmediatamente para reportar la situación. Si su pariente está registrado en el programa "Hospice," será usted instruído de llamar al numero emergente de "Hospice" en lugar de "911." El personal de "Hospice" vendrá al hogar, asistirá con los detalles y ofrecerá apoyo por mientras que usted espera.



## PROFESIONALES RESPONDIENDO

- Habrá varias personas del equipo médico emergente que respondan al lugar donde el difunto murio para revisar el incidente. Cuándo el equipo de "911" respondan, ellos notificarán a los oficiales de justicia apropriados (el departamento de policía o sheriff).
- El médico primario del difunto será notificado para que se determine si anticipaba la muerte y para preguntarle si está dispuesto a firmar el certificado de defunción. Si el médico indica que la muerte fue un evento esperado (así como una enfermedad terminal) entonces se harán arreglos para que el difunto sea transladado a una mortuoria o funeraria asignada. Si la muerte no aparece razonable, se vé sospechosa o el médico no conoce el paciente tan bien como para firmar el certificado de defunción o no puede ser localizado, entonces los oficiales de justicia llamarán a la oficina del médico forense.
- El médico forense transportará el cuerpo a su oficina para determinar la causa de la muerte que quizás pueda incluír una autopsia. El cuerpo del difunto no se permitirá entregar a la familia hasta que se determine la causa de muerte pero esto no tardará más que unos cuántos días, hay veces menos dependiendo en las circumstancias.

## PROCESO QUE CONSUME TIEMPO

El proceso puede durar varias horas. Es muy difícil perder un ser querido cuándo esto está anticipado y tal vez aún más cuándo la muerte es inesperada. Es muy importante permanecer con calma y que no altere la situación hasta que el equipo de "911" y los oficiales de policía lleguen. Es importante que considere llamar a un pariente o amistad cercana que esté dispuesto a permanecer con usted y darle apoyo por mientras que espera que terminen todo los procedimientos. Tome en cuenta que esto probablemente tardará varias horas y aunque uno crea que está preparado, es muy posible que esté en el estado de choqué.

## LA PRECENSIA DE PERSONAS RESPONDIENDO AL HOGAR

El equipo auxiliador sanitario de "911" consiste de dos a tres miembros. El cuerpo de policía a veces tendrá uno o dos oficiales respondiendo, a menos que usted sospeche que un crimen haya ocurrido, entonces se presentarán uno o dos detectives . Si aparece que las circumstancias requierán más investigación o documentación, entonces varios oficiales del departamento forense también estarán presente para tomar fotos, guellas y conducir una investigación más extensiva. También se presentará el médico del difunto o el médico forense y/o el personal de la mortuoria para transportar el cuerpo.

## CLASES DE PREGUNTAS QUE SE PUEDAN PREGUNTAR

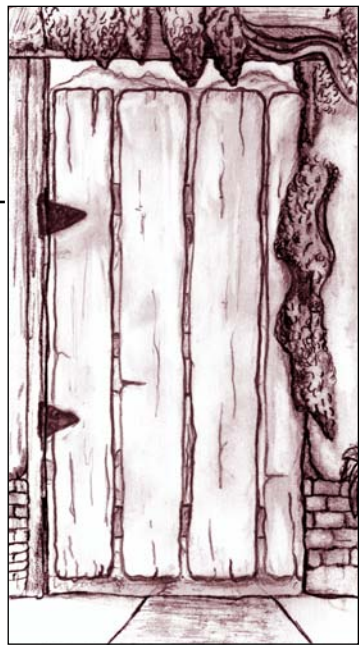
El equipo emergente preguntará el historial médico del difunto, los medicamentos qué tomabá y para qué clase de condiciones médicas, qué tipo de tratamiento se sometía como también los nombres y números de teléfono de todos los médicos atendiendo al difunto. Le pueden preguntar sobre el bienestar del pariente, qué tanta asistencia necesitaba para conducir sus actividades a diario y otras preguntas de rutina que puedán clarificar las circumstancias alrededor de la muerte.

## AUTOPSIA

Normalmente la oficina del médico forense retiene el cuerpo del difunto solo hasta que se nombre una mortuoria y solo conduce una investigación o autopsia cuándo hay bastante información que indique que haya ocurrido un crimen. Ellos están bien entrenados para tomar en cuénta las diferencias de religión y cultura y hacen todo el esfuerzo posible para honrar las creencias que se opongan a una autopsia aunque cuándo es necesario, la autopsia será parte del procedimiento.

# END OF LIFE DECISIONS

*helping older relatives or friends make more informed choices about end of life decisions*



## FREQUENTLY ASKED QUESTIONS ABOUT BURIAL ARRANGEMENTS

A caregiver faces many difficult and rewarding challenges. Among them are preparing your relative, other family members and yourself for the end of life transition.

### ❖ Even though we don't like to think about it, we will eventually have to face the death of a loved one. How do we prepare?

Open a conversation with your relative to determine if end of life arrangements have been made (i.e., Advance Directives, funeral arrangements, religious services, etc.). If so, ask if they will share with you what type arrangements have been made and where the documents are located, or if not, what their wishes are. There are certain decisions that will have to be made about burial arrangements, such as:

- Does your family member want to have a burial or cremation, or have they chosen to donate their body to medical education?
- Are there religious beliefs that will effect this decision?
- Has a mortuary or funeral home been chosen? If yes, has your relative completed a form stating their wishes that is on file at the mortuary or funeral home?
- What characteristics are important, i.e., location, services offered, pleasant surroundings, etc?
- If your relative is planning a burial, will it be local or somewhere else? Has your relative or another family member purchased a cemetery plot or does one need to be chosen?

Other details that need to be considered include:

- Date and location of services, viewing, receptions, choice of officiator(s), type of casket, flowers, music, etc.
- Writing and placement of obituaries or funeral notices, including information such as: full legal name, birth date, place of birth, names of family members; newspapers both locally and in other towns for posting funeral or obituary notices
- The number of death certificates that will be required to inform appropriate agencies and groups (i.e., Social Security, insurance policies, trusts, bank accounts, etc.)

To become more informed on the various burial choices, and details such as locating cemetery plots, casket options or cremation specifics, you can call or visit your local mortuaries or contact the Arizona Funeral Directors Association. Many have brochures and pamphlets that provide information about the options available. Most mortuaries will provide a tour and answer questions about expenses, as well as payment options and advanced planning services. There are also funeral associations that can help lower the cost of funerals through memberships and some religious congregations will assist members. Mortuaries are always ready to assist you in advance or after a recent loss.

### ❖ What do funerals and cremations cost?

Since costs vary, you may want to compare prices and get detailed information about all involved costs. Be aware that there are often tremendous differences in prices. Funeral directors are required to give you a price sheet with detailed funeral costs, and to give prices over the phone if you ask. Be sure to ask about any extra fees that may not be included in the prices. For instance, obituary notices are not required. As a matter of public record, the death will be recorded and the name, age and occupation of the deceased printed in the newspaper. However, if you choose to have an obituary the funeral home

will assist the family in preparing and submitting the notices. The cost of notices vary based on the length (charge by word) and the number of days it is posted in the newspapers selected locally and/or in other cities. There are also variations in the costs of caskets. Usually, only the most expensive caskets are displayed in the funeral home. If interested, ask the funeral director if less expensive alternatives are available. In fact, it is possible to purchase low cost caskets through casket outlets that are not associated with a specific funeral home. Also, some mortuaries and funeral homes will rent their more expensive caskets to be used only during memorial services or viewing. This option allows the family of the deceased to purchase a less expensive casket for final internment. Carefully review the terms offered as part of "package deals". Sometimes additional services are included that may not be required.

According to the Funeral Consumers Alliance of Southern Arizona, the average cost of a "traditional" funeral in the U.S. is now over $6,000. A more extravagant funeral could cost over $10,000. Depending on the arrangements and preferences, the costs for a direct burial can be less than $500, but this does not include the cemetery plot, obituary notices, copies of death certificate and other details. A direct cremation may be available for less than $500 but usually the cost does not exceed $1,000. The price for a simple cremation package, called a "Direct Cremation", should be listed on the pricing sheet.

### ❖ Who pays for funeral expenses?

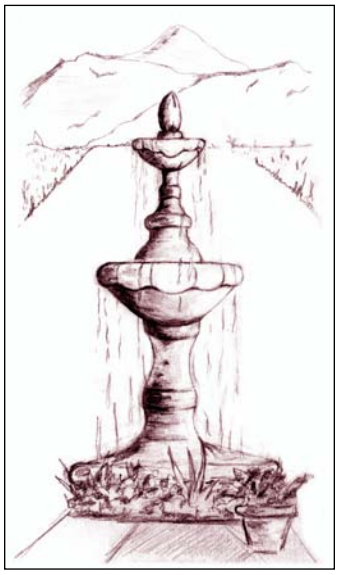
Funeral costs can be borne by the estate of the person who died, or may be paid by advanced planning contracts or life insurance plans. Sometimes family members choose to bear the expense. Social Security does provide a lump sum funeral allowance for burial in the amount of $250 for eligible recipients paid either to the surviving spouse or a child less than 18 years of age. The Veterans Administration (VA) also provides a funeral/burial benefit for persons who have served in the military and their spouses. If your relative is in the process of applying or may need to apply to ALTCS there are a number of rules that pertain to burial plans. Please contact Pima Council on Aging or any Arizona Funeral Association for more information.

In some limited circumstances arrangements can be made for people who die without any resources or ability to pay. The funeral director can provide the necessary information about indigent burials. In Pima County, the Office of the Public Fiduciary handles indigent burials (Ph: (520) 740-5454).

### ❖ What should we know about cremation as an option to burial?

Cremation as an option is growing. The number of cremations grew from less than 5% of all U.S. deaths in 1970 to more than 25% in 2000. In part this increase is due to greater awareness of cremation as an alternative; its relatively low cost compared with burial; and the growing number of older people who have retired far away from their hometowns and family burial sites. However, more comprehensive cremation laws are needed to address issues such as licensing, inspections, recordkeeping, disposition and identification of remains, and penalties for violations. Things to consider:

- Not all crematories are licensed. In most states those affiliated with cemeteries or funeral homes are required to be licensed.
- You don't need to go through a funeral home to make arrangements. Obtaining cremation services directly from a crematory or through a cremation society can be less expensive.
- Use a crematory that is licensed and undergoes public inspection; inquire about the training of facility staff.
- Embalming is an extra expense and isn't necessary for a timely cremation.



### ❖ What if your loved one wants to donate their body to science or medical education?

Your loved one has to pre-register or enroll with a program in their area. There are a few circumstances under which the medical program may not be able to accept their body; therefore burial arrangements would need to be made. Some exclusions include: the removal of an organ or part of the body, decomposition of the body, severe trauma, suicide, or the presence of contagious diseases.

### ❖ What if we need to transport the body out of state for burial?

Your local mortuary will assist you in preparing the body and arranging for transportation to the receiving location. The mortuary will acquire the death certificates, arrange the appropriate permits and air transportation on your behalf.

## HELPFUL POINTERS FOR CAREGIVERS:

- With the help of your relative, keep a record of the basic medical conditions, medications, physician names, emergency contacts and telephone numbers of family and friends your loved one wishes to be called in the event of their death.
- Together with your relative prepare a note card with information on any prearrangements made for funeral plans, mortuary preferences, burial plots, life insurance plans, etc. Also check with local mortuaries or funeral associations for a copy of helpful planning guides.
- If your loved one has a terminal illness, become informed about the option of hospice care.
- Contact a local support group for grief and loss to help you and all family members during this most stressful and emotionally difficult time.

*"Dance like no one is watching,*
*Love like you'll never be hurt,*
*Sing like no one is listening,*
*Live like it's heaven on earth."*
*~William Purkey*

## RESOURCES

- Funeral Consumer Alliance of Southern Arizona
  7030 E. Broadway Blvd., Ste. 220
  Tucson, AZ 85710
  Phone: (520) 721-0230
  www.funerals.org/tucson/
- Arizona State Board of Funeral Directors & Embalmers
  1400 W. Washington, Suite 230
  Phoenix, AZ 85007
  Phone: (602) 542-3095; www.funeralbd.state.as.us
- Arizona Funeral Directors Association
  Box 414, 2753 E. Broadway, Suite 101
  Mesa, AZ 85204-1579
  Phone: (480)649-1144; Fax: (480)649-0362
  Email: www.azfda@msn.com, Website: www.azfda.org
- Cremation Association of North America
  Phone: (312) 321-6806 www.cremationassociation.org
- Federal Trade Commission, "Funerals: A Consumer Guide"
  www.ftc.gov/bcp/conline/pubs/services/funeral.htm
- Funeral Consumer Alliance
  toll free (800) 765-0107; or (800) 458-5563
  www.funerals.org/
- Body Donation Program
  University Medical Center, University of Arizona
  1501 N. Campbell Ave
  Tucson, Arizona 85719,
  Phone: (520) 626-1801
- International Cemetery and Funeral Association
  toll free 800-645-7700; www.icfa.org
- National Funeral Directors Association
  toll free line (800) 228-6332; www.nfda.com
- Pima Council on Aging
  8467 E. Broadway Blvd.
  Tucson, Arizona 85710-4009
  Phone: (520) 790-7262; www.pcoa.org

**Hospice & Palliative Care for grief & loss support groups**
(check your local directory or call Pima Council on Aging)

If dissatisfied with funeral home services contact:

- Funeral Ethics Association
  215 South Grand Ave.
  West; Springfield, IL 62704
  Website: www.fea.org
- Arizona Funeral Directors Association
  Box 414, 2753 E. Broadway, Suite 101
  Mesa, AZ 85204-1579
  Phone: (480)649-1144; Fax: (480)649-0362
  Email: www.azfda@msn.com, Website: www.azfda.org

*Prepared for Pima Council on Aging by the Arizona Center on Aging, the University of Arizona®*

# END OF LIFE DECISIONS: BURIAL ARRANGEMENTS

*helping older relatives or friends make more informed choices about end of life decisions*

A caregiver faces many difficult and rewarding challenges. Among them are preparing your relative, other family members and yourself for the end of life transition.

## PREPARATIONS & ARRANGEMENTS

Open a conversation to discuss your relative's wishes. Consider asking the following questions:

- Has your relative made end of life arrangements? Are they willing to share with you arrangements that have been made? Where are the documents located?
- Does your relative want to have a burial, cremation or donate their body to medical education? Are there religious beliefs that will affect this decision? If a burial is planned, will it be local or somewhere else? Has a cemetery plot been purchased?
- What other considerations are important, such as: location of services, viewing, receptions, choice of officiator(s), type of casket, flowers, music, obituaries or notices, number of death certificates required, etc.

To become more informed on the various burial choices and details such as locating cemetery plots, casket options or cremation specifics, you can call or visit your local mortuaries or contact the funeral association.

## FUNERAL & CREMATION COSTS

Since costs vary you may want to compare prices. Most mortuaries will answer questions about expenses, payment options and advanced planning services. Funeral directors are required to give you a price sheet with detailed funeral costs, and give prices over the phone if you ask. Be sure to ask about any extra fees that might be included in the prices. **Cost of a casket -** usually only the most expensive caskets are displayed in the funeral home. Less expensive alternatives are available. Low cost caskets can be purchased through casket outlets that are not associated with a specific funeral home. Some mortuaries will rent their more expensive caskets to be used only during memorial services or viewing. **Cost of a funeral –** a "traditional" funeral may cost over $6,000. A Direct Burial can be less than $500 not including the cemetery plot, obituary, death certificates and other details. A Direct Cremation may cost less than $500 but usually does not exceed $1,000.

## PAYMENT FOR FUNERAL EXPENSES

Funeral costs can be borne by the estate of the person who died, may be paid by advanced planning contracts, life insurance plans or family members. Social Security provides a funeral allowance in the amount of $250 for eligible recipients paid either to the surviving spouse or a child less than 18 years of age. The Veterans Administration (VA) provides a burial benefit for military veterans and their spouses. If your relative is in the process of applying or may need to apply to ALTCS there are rules that pertain to burial plans (contact Pima Council on Aging or the Arizona Funeral Directors Association for more information). Some funeral associations and religious congregations assist members with funeral expenses. In Pima County, inquiries about indigent burials (for persons who die without any resources or ability to pay) should be made to the Office of the Public Fiduciary (Ph: (520) 740-5454).

## CREMATION AS AN OPTION TO BURIAL

Greater awareness of cremation as an alternative to burial is growing in part due to its relatively low cost compared to burial. Things to consider include:

- Not all crematories are licensed. In most states those affiliated with cemeteries or funeral homes are required to be licensed.
- You don't need to go through a funeral home to make arrangements. Obtaining cremation services directly from a crematory or through a cremation society can be less expensive.
- Use a crematory that is licensed and undergoes public inspection; inquire about the training of facility staff.
- Embalming is an extra expense and isn't necessary for a timely cremation.

## BODY DONATION

Your loved one has to pre-register or enroll with a medical program in their area. The medical program may not be able to accept their body under certain circumstances, such as: removal of an organ or part of the body, decomposition of the body, severe trauma, suicide or the presence of contagious diseases.

## OUT OF STATE BURIAL

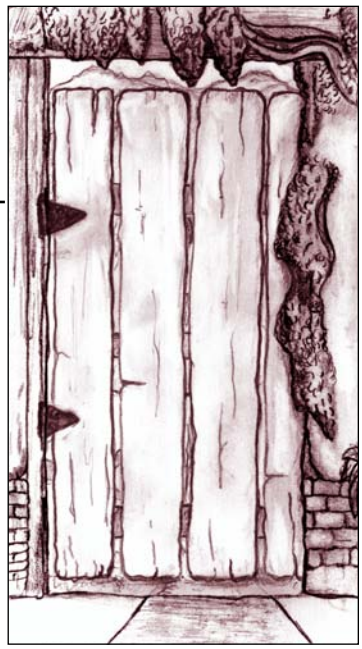
Your local mortuary will assist you in preparing the body and arranging for transportation to the receiving location. The mortuary will acquire the death certificates, arrange the appropriate permits and air transportation on your behalf.

## HELPFUL POINTERS FOR CAREGIVERS

- With the help of your relative keep a record of the telephone numbers of family and friends your loved one wishes to be called in the event of their death.
- Together with your relative prepare a note card with information related to: end of life arrangements, mortuary preferences, burial plots, life insurance plans, etc. Check with local mortuaries or funeral associations for a copy of helpful planning guides.
- If terminally ill, your relative may want to speak with their physician about hospice care.
- Contact a local support group for grief and loss to help you and all family members during this most stressful and emotionally difficult time.

# DECISIONES DE FIN DE VIDA

*Ayudando a parientes o amistades envejecidos hacer mejor selecciones informativas sobre las decisiones de fin de vida*



## PREGUNTAS QUE SURGEN PREGUNTAR FRECUENTEMENTE SOBRE LOS ARREGLOS DE SEPULTURA

Un cuídador se enfrentará a muchos retos trabajosos aunque también será recompensado. Entre ellos se encuentra la preparación de sus parientes, otros miembros de familia y si mismo para la transición de fin de vida.

❖ **Aunque no nos gusta pensar de ello, tarde or temprano nos enfrentaremos con la muerte de mi ser querido. ¿Como podemos prepararnos?**

Inicie una conversación con su pariente para determinar si se han hecho arreglos de fin de vida (por ejemplo Directivas Avanzadas, preparación de funeral, servicios religiosos, etc.). Si estos se han hecho, pregunte si pueden compartir con usted que tipos de arreglos y donde se encuentran estos documentos. Si no se han hecho, pregunte lo que desea la persona. Hay unas ciertas decisiones que se deben hacer sobre los arreglos de funeral como:

- ¿Quiere su miembro de familia ser sepultado(a) o incinerado(a) o quiere donar su cuerpo para el estudio de medicina?
- ¿Hay creencias religiosas que efecten esta decisión?
- ¿Ha escogido una mortuoria o funeraria? Si acaso, ha llenado su pariente una forma delatando sus deseos que esté archivado en la mortuoria o funeraria?
- ¿Qué características son importantes, por ejemplo-el sitio, los servicios rendidos, un ambiente agradable, etc.?
- Si su pariente desea ser sepultado, ¿será localmente o en otro sitio? ¿Ha comprado su pariente o otro miembro de familia un lugar en el cementerio o aún se debe comprar?

Otros detalles que deben ser considerados incluyen:

- Fecha y el lugar de servicio, la velación, recepción, el oficiante o sacerdote que ha escogido, el tipo de ataúd, flores, música, etc.
- Las publicaciones necrológicas y su lugar en la necrología de un periódico o notificantes de funeral que quizás incluya la seguiente información: el nombre legal y completo, fecha de nacimiento, lugar de nacimiento, nombres de familia, los nombres de los periódicos, ya sean local o en otras ciudades, donde deben ser publicado en la necrología.
- La cantidad de certificados de defunción que se requiere para distribuír a las agencias y los grupos adecuados como el departamento de seguro social, pólizas de seguro, fideicomiso, cuentas de banco, etc.

Para obtener más información sobre las selecciones de las varias maneras de sepultura y detalles, por ejemplo - como localizar el lugar de sepultura en un cementerio, opciones de ataúd o detalles de incineración, puede usted llamar o visitar su funeraria local o ponerse en contacto con la Asociación de Directores de Funerarias de Arizona o mortuorias. Muchos de estos locales publicán folletos con información sobre las opciones disponibles. Muchas mortuorias ofrecen visitas en las cual pueden contestar sus preguntas sobre los gastos, así como las opciones de pago y sus servicios de planificación por adelantado. También hay asociaciones de funeral que pueden ayudar a reducir el costo de un funeral si usted es socio. Las mortuorias siempre estan listas para asistirle adelantado o despues de su reciente perdida de alguien.

## ❖ ¿Cuánto cuesta un funeral o incineración?

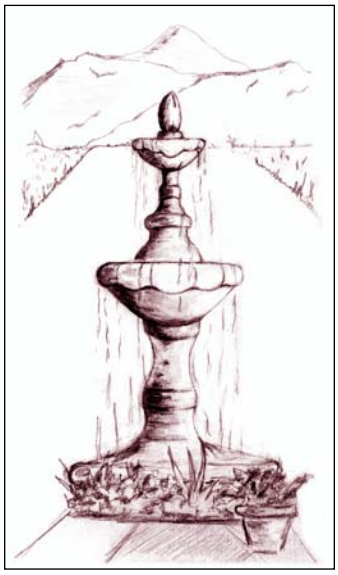
Es muy importante que compare los precios y gastos y obtenga información detallada de todos los cobros asociados a un funeral porque los precios varían de compañía a compañía. Tome en cuenta que hay tremendas diferencias de precios. Directores de funerales estan obligados en enseñar una lista por escrito de los precios con los detalles de gastos asociados con un funeral y también de darle estos precios por teléfono si usted pregunta por ellos. Asegure de preguntar por todos los cobros extras que tal vez no esten incluídos en los precios. Por ejemplo, la notificación en un obituario no se requiere. En cuanto lo que se requiere para el archivo público, el fallecimiento será apuntado y el nombre, la edad y la profesión del fallecido será publicado en los periódicos. Sin embargo, si usted elige en tener un obituario, la funeraria puede ayudar a la familia en preparar y someter los avisos. Habrá variedad en el cobro de los avisos porque dependen en que tan largo (se cobra por palabra) y cuantos días el aviso aparecerá en los periódicos localmente y/o en otras ciudades. También hay variedad en el costo de los ataúds. Por costumbre, las funerarias exhiben los ataúds más caros. Si le interesa, pregunte si hay opciones menos caras. En realidad, es posible conseguir ataúds menos caros en tiendas de ataúds (casket outlets) que no esten asociados con una funeraria en particular. También muchas funerarias y mortuorias alquilan sus ataúds más caros para que se puedan usar solo durante los servicios. Esta opción permite a las familias del fallecido comprar un ataúd menos caro para sepultar.

Revise cuídadosamente los términos ofrecidos como el "paquete completo." Algunas veces muchos de los servicios adicionales que están incluídos no son necesarios.

En acuerdo con La Alianza de Consumidores de Funerales de Sur Arizona (Funeral Consumers Alliance of Southern Arizona), el costo promedio o precio normal de un funeral "tradicional" en los Estados Unidos hoy es más de $6,000. Un funeral más extravagante puede costar más de $10,000. El costo de una sepultación directa puede ser menos de $500 dependiendo en las preferencias y las clases de arreglos pero esto no incluye el lugar de sepultura, los avisos obituarios, copias de certificado de defunción y otros detalles. Una incineración directa puede también estar al alcance por menos de $500 aunque por común el costo no excede más que $1,000. El precio por "el paquete" de una incineración sencilla referido como "Incineración Directa" (Direct Cremation) debe ser indicado en la lista de precios.

## ❖ ¿Quién paga los gastos de un funeral?

Los gastos de un funeral pueden ser sostenidos por la herencia de la persona fallecida o se pueden pagar por adelanto usando un contrato de planificación avanzada o también se puede pagar por el plan de seguro de vida. Hay veces que los miembros de familia escogen sostener todos los gastos. El departamento de Seguro Social (Social Security Department) puede rendir una sola cantidad de $250 para el proposito único de sepultura para aquellas personas que sean elegibles y se les paga a el cónyuge sobreviviente o al hijo(a) menor de 18 años de edad. La Administración de Veteranos (Veterans Administration) también provée un beneficio de funeral o sepultura a aquellas personas y sus cónyuges que llegaron a servir en el ejercito militar de los Estados Unidos. Si su pariente está en el proceso de solicitar o necesita solicitar para ALTCS, hay varias reglas que pertenecen a los planes de funeral o sepultura. Por favor pongase en contacto con el Concilio de Envejecimiento de Pima (Pima Council on Aging) o cualquiera Asociación de Funerales de Arizona (Arizona Funeral Association) para más información.



En ciertas circumstancias limitadas se pueden hacer arreglos para personas que hayan fallecido sin ningun recurso o habilidad de pago. El director de funeral puede proveer la información necesaria sobre sepultura indígena. En el condado de Pima, la Oficina Pública de Fiduciario se encarga de sepultaciones indígenas. (Teléfono (520)740-5454).

### ❖ ¿Qué debemos saber sobre la incineración como una opción de sepultura?

La opción de incineración está aumentando. El número de incineraciones crecio desde menos de 5% de todas las muertes en los Estados Unidos en 1970 hasta más de 25% en el año 2000. En parte este crecimiento se debe al aumento del conocimiento de incineración como una opción; es relativamente menos gasto en comparación a un entierro; y en el aumento de la cantidad de gente jubilada que vive lejos de sus tierras y sitios de sepultura. Sin embargo, se necesita más leyes comprensivas de incineración que dediquen más atención a los problemas con licensias, inspección, registros, disposición y identificación de los restos, y multas por delitos. Algunas cosas que se deben considerar:

- No todos los crematorios tienen licensia. En casi todos los estados, aquellos crematorios afiliados con un cementerio o una funeraria/mortuoria se les exigen tener una licensia.
- No se necesita ir a una funeraria para hacer arreglos. Puede ser menos gasto obtener los servicios de incineración de un crematorio o asociación de crematorios directamente.
- Consiga un crematorio que tenga licensia y se someta a inspecciones públicas; pregunte sobre el entrenamiento del personal de la instalación.
- El embalsamiento es un costo adicional y no es necesario si se incinera el cuerpo a tiempo.

### ❖ ¿Qué si nuestro ser querido desea donar su cuerpo para la educación científica o médica?

El ser querido debe registrarse antes o matricularse en un programa en su area. Hay unas cuantas circumstancias que los programas médicos no pueden aceptar el cuerpo del ser querido; entonces se tendran que hacer planes o arreglos de entierro o incineración. Algunas exclusiones incluyen: el removimiento de una parte del cuerpo o órgano, la descomposición del cuerpo, trauma severa, el suicidio, o la presencia de enfermedades contagiosas.

### ❖ ¿Qué si tenemos que transportar el cuerpo de nuestro ser querida fuera del estado?

Su mortuoria local puede asistirle en preparar el cuerpo y hacer los trámites para transportarlo al sitio deseado. La mortuoria obtendrá los certificados de fallecimiento, arreglará para que se obtengan los permisos adecuados y la transportación aérea de su parte.

### CONSEJOS QUE PUEDEN AYUDAR AL CUIDADOR:

- Con la ayuda de su pariente, mantenga un historial de las condiciones médicas basicas, medicamentos, nombres de médicos, los contactos de emergencia y números de teléfono de la familia y amistades que su ser querido desea que se les avise en caso de su muerte.
- Prepare junto con su pariente una carta de anotaciones con toda la información de cualquier arreglo que se haga hecho de antemano con respecto a su funeral, preferencia de mortuoria, sitio de entierro, seguro de vida, etc. Obtenga de su mortuoria local una copia de guía muy útil para la planificación.
- Si su ser querido tiene una enfermedad terminal, preguntele al médico de su pariente sobre la opción que un “Hospice Care” le puedá ofrecer. Un “Hospice” es un asilo para pacientes con enfermedades terminales.
- Pongase en contacto con un grupo de apoyo local que puedá ayudar con la perdida y el dolor de usted y de todos los miembros de la familia durante estos tiempos tan dificiles emocionalmente y llenos de tensión.

## PARA MÁS INFORMACIÓN, PONGASE EN CONTACTO CON:

- "Funeral Consumer Alliance of Southern Arizona"
  (La Alianza Para El Consumidor De Funerales de Sur Arizona),
  7030 E. Broadway Blvd., Suite 220
  Tucson, Arizona 85710
  Teléfono (520)721-0230
  sitio en el "Internet" www.funerals.org/tucson/
- "Cremation Association of North America"
  (La Asociación de Crematorio de Norte America)
  Teléfono (312)321-6806
  sitio en el "Internet" www.cremationassociation.org
- "Federal Trade Commission,"
  'Funerals: A Consumer Guide'"
  (La Comisión Federal de Negocios,
  "Funerales: Un Guía Para El Consumidor"), sitio en el "Internet"
  www.ftc.gov/bcp/conline/pubs/services/funeral.htm
- "Funeral Consumer Alliance"
  (La Alianza de Consumidores de Funerales),
  llamada gratis a (800)765-0107 o (800)458-5563
  sitio en el "Internet" www.funerals.org/
- "Body Donation Program"
  (El Programa de Donación Del Cuerpo)
  University Medical Center
  Universidad de Arizona
  1501 N. Campbell Ave., Tucson, AZ 85719
  Teléfono (520)626-1801
- "International Cemetery And Funeral Association"
  (La Asociación Internacional de Cementerios y
  Funerales), llamada gratis (800)645-7700,
  sitio en el "Internet" www.icfa.org
- "National Funeral Directors Association"
  (La Asociación Nacional de Directores de Funerales),
  llamada gratis (800)228-6332
  sitio en el "Internet" www.nfda.com
- "Pima Council on Aging"
  (El Concilio de Envejecimiento de Pima),
  8467 E. Broadway Bvd., Tucson Arizona 85710-4009

Teléfono (520)790-7262; sitio en el "Internet" www.pcoa.org

**Asilo Para Pacientes Con Enfermedades Terminales ("Hospice"), Cuídado Paliativo ("Palliative Care") y Para Los Grupos Dedicados A Dar Apoyo Con La Perdida Y La Aflicción**

(Busque en su guía telefonica local o llame al
Concilio de Envejecimiento de Pima,
"Pima Council on Aging")

Si está insatisfecho con los servicios de una mortuoria o funeraria, escriba:

- "Funeral Ethics Association"
  (La Asociación Etica de Funerales),
  215 South Grand Ave. West
  Springfield IL 62704 o al sitio de "Internet": www.fea.org

*Preparado para El Concilio de Envejecimiento de Pima (Pima Council on Aging) por El Centro de Envejecimiento de Arizona (Arizona Center on Aging), de la Universidad de Arizona®*

# DECISIONES DE FIN DE VIDA: ARREGLOS DE SEPULTURA

*Ayudando a parientes o amistades envejecidos hacer mejor selecciones informativas sobre las decisiones de fin de vida*

Un cuídador se enfrentará a muchos retos trabajosos aunque también será recompensado. Entre ellos se encuentra la preparación de sus parientes, otros miembros de familia y usted para la transición de fin de vida.

## PREPARACION Y ARREGLOS

Inicie una conversación con su pariente para discutir sus deseos. Considere preguntar las siguientes preguntas:

- ¿Ha hecho su pariente arreglos de fin de vida? ¿Pueden compartir con usted que tipos de arreglos se han hecho? ¿Donde se encuentran estos documentos?
- ¿Quiere su miembro de familia ser sepultado(a) o incinerado(a) o quiere donar su cuerpo para el estudio de medicina? ¿Hay creencias religiosas que efecten ésta decisión? Si su pariente desea ser sepultado, ¿será localmente o en otro sitio? ¿Ha comprado su pariente o otro miembro de familia un sitio en el cementerio?
- ¿Qué otras consideraciones son importantes, por ejemplo el sitio de los servicios, la velación, recepción, el oficiante o sacerdote que ha escogido, el tipo de ataúd, flores, música, las publicaciones necrológicas o notificantes, la cantidad de certificados de defunción que se requiere, etc.?

Para obtener más información sobre las selecciones de las varias maneras de sepultura y detalles por ejemplo - como localizar el lugar de sepultura en un cementerio, opciones de ataúd o detalles de incineración, puede usted llamar o visitar su funeraria local o ponerse en contacto con la asociación de Funerarias.

## EL COSTO DE UN FUNERAL O INCINERACION

Es muy importante que compare los precios y gastos y obtenga información detallada de todos los cobros asociados a un funeral porque los precios varían de compañía a compañía. Muchas funerarias responden as sus preguntas sobre los gastos, opciones de pago y la planificación de servicios en avanzado. Directores de funerales estan obligados en enseñar una lista por escrito de los precios con los detalles de gastos asociados con un funeral y también de darle estos precios por teléfono si usted pregunta por ellos. Asegure de preguntar por todos los cobros extras que tal vez esten incluídos en los precios. **Costo de los ataúds -** por costumbre, las funerarias exhiben los ataúds más caros. Si hay opciones menos caras. Se puede conseguir ataúds menos caros en tiendas de ataúds (casket outlets) que no esten asociados con una funeraria en particular. También muchas funerarias y mortuorias alquilan sus ataúds más caros para que se puedan usar solamente durante los servicios. **Costo de un funeral –** el costo promedio o precio normal de un funeral "tradicional" es más de $6,000. El costo de una sepultura directa puede ser menos de $500 pero esto no incluye el lugar de sepultura, los avisos obituarios, copias de certificado de defunción y otros detalles. Una incineración directa puede también estar al alcance por menos de $500 aunque por común el costo no excede más que $1,000.

## PAGO DE LOS GASTOS DE UN FUNERAL

Los gastos de un funeral se pueden pagar por la herencia de la persona fallecida, por adelanto usando un contrato de planificación avanzada, por el plan de seguro de vida o por miembros de familia. El departamento de Seguro Social (Social Security Department) puede rendir una sola cantidad de $250 para el proposito único de sepultura para aquellas personas que sean elegibles y se les paga al cónyuge sobreviviente o al hijo(a) menor de 18 años de edad. La Administración de Veteranos (Veterans Administration) también provée un beneficio de funeral o sepultura a aquellas personas y sus cónyuges que llegaron a servir en el ejercito militar de los Estados Unidos. Si su pariente está en el proceso de solicitar o necesita solicitar para ALTCS, hay varias reglas que pertenecen a los planes de funeral o sepultura. Por favor pongase en contacto con el Concilio de Envejecimiento de Pima (Pima Council on Aging) o cualquiera Asociación de Funerales de Arizona (Arizona Funeral Association) para más información. Ciertas asociaciones de funeral y grupos religiosos también asisten a miembros con los gastos de un funeral. En ciertas circumstancias limitadas se pueden hacer arreglos para personas que hayan fallecido sin ningun recurso o habilidad de pago. En el condado de Pima, la Oficina Pública de Fiduciario se encarga de sepulturas indígenas. (Teléfono (520)740-5454).

## INCINERACION COMO UNA OPCION DE SEPULTURA

La opción de incineración está aumentando en parte porque el conocimiento de incineración como una opción es relativamente menos gasto en comparación a un entierro. Algunas cosas que se deben considerar:

- No todos los crematorios tienen licensia. En casi todos los estados, aquellos crematorios afiliados con un cementerio o una funeraria/mortuoria se les exigen tener una licensia.
- No se necesita ir a una funeraria para hacer arreglos. Puede ser menos gasto obtener los servicios de incineración de un crematorio o asociación de crematorios directamente.
- Consiga un crematorio que tenga licensia y se someta a inspecciones públicas; pregunte sobre el entrenamiento del personal de la instalación.
- El embalsamiento es un costo adicional y no es necesario si se incinera el cuerpo a tiempo.

## LA DONACION DEL CUERPO

El ser querido debe registrarse antes o matricularse en un programa en su area. Algunas exclusiones que los programas médicos no pueden aceptar el cuerpo del ser querido pueden ser: el removimiento de una parte del cuerpo o órgano, la descomposición del cuerpo, trauma severa, el suicidio, o la presencia de enfermedades contagiosas.

## SEPULTURA FUERA DEL ESTADO

Su mortuoria local puede asistirle en preparar el cuerpo y hacer los trámites para transportarlo al sitio deseado. La mortuoria obtendrá los certificados de fallecimiento, arreglará para que se obtengan los permisos adecuados y la transportación aérea de su parte.

## CONSEJOS QUE PUEDEN AYUDAR AL CUIDADOR

- Con la ayuda de su pariente, mantenga una lista de números de teléfono de la familia y amistades que su ser querido desea que se les avise en caso de su muerte.
- Prepare junto con su pariente una carta de anotaciones con toda la información de cualquier arreglo que se haga hecho de antemano con respecto a su funeral, preferencia de mortuoria, sitio de entierro, seguro de vida, etc. Obtenga de su mortuoria local una copia de guía muy útil para la planificación.
- Si su ser querido tiene una enfermedad terminal, su pariente puede querer preguntar a su médico sobre la opción que el cuídado de “Hospice” le puedá ofrecer.
- Pongase en contacto con un grupo de apoyo local que puedá ayudarle a usted y a su familia con el sufrimiento y la perdida durante estos tiempos tan trabajosos emocionalmente y llenos de tensión.