

# Voices of Strength

**Living After Cancer Treatment** 





# You are not alone.

More than 10 million cancer survivors live in the United States today, and 3 out of 4 families will help care for a family member with cancer.

Being a cancer survivor means more than just living. It means living life your way.

You can use this booklet to help you identify your concerns and figure out where to go for help. You can also learn from other cancer survivors what has helped them.

# How to use this booklet:

- 1. Go through this booklet and check off the physical, emotional and practical concerns you have.
- **2.** Take this booklet with you the next time you see your healthcare provider.
- 3. Use this booklet to talk to your healthcare provider or to call the resources listed on pages 16–20.



# Physical Changes Pain, Body, Lifestyle

After treatment, you may have special needs in caring for your body. Ask your healthcare provider what changes in your body you can expect.

would like help with or write down your own concerns.				
Pain or Swelling  ☐ I have pain that does not go away. ☐ I have swelling in parts of my body.				
<ul> <li>Body Changes</li> <li>I am not sure how the medicines I am taking will affect my body.</li> <li>My feelings about my body have changed.</li> <li>I feel tired often.</li> <li>I have trouble remembering things and my mind works more slowly than before.</li> </ul>				
Lifestyle  I want to know how much I should exercise.  I want to know what type of diet I should follow.  I am having changes in my intimate life.  Other				

I am healthier now than I was before the cancer. Stronger.

The cancer was just something to wake me up.

Ilene, cancer survivor

# Physical Changes

Pain, Body, Lifestyle

Your healthcare provider can help you understand how to address these concerns and how to find resources to help you. You may not feel like you need help. But many survivors have found that receiving help from these services made their lives easier.



Here are some examples of services that help cancer survivors. Check the box next to the service you would like to learn more about.

# **Pain or Swelling**

- I want to learn more about ways to relieve pain.
- I want to know about working with a traditional healer.
- □ I want to know about other services such as massage, aromatherapy or yoga.

# **Body Changes**

- I want help restoring my strength and my ability to move around.
- I would like information about my fertility options.

# Lifestyle

- I would like a nurse or other caregiver to help me in my home.
- I want help with tasks like cleaning or cooking meals.



# **Emotional Changes**

Feelings, Relationships, Life Changes

When you finish your treatments, you may wonder what to expect. You may have many emotions, and new concerns may come up at any time. This is normal. Some people fear that the cancer will return. Some people find that different things are now important to them. Relationships with family and friends may change.



Make a check next to the things you would like help with or write down your own concerns.

# **Feelings**

- □ I am worried that the cancer might return.
- □ I am feeling sad or depressed.

# Relationships

- I am not sure how to talk to my friends and family about my cancer.
- I am not sure how to talk to my children about my cancer.

# Life Changes

- □ The things that are important to me have changed.
- My cancer has changed my spirituality.
- □ I don't know what to expect.

### Other

I am a storyteller. I come to the support group.
I listen. I participate.
Sometimes that is the learning tool and the best form of support.

Rosanne, cancer survivor

# **Emotional Changes**

Feelings, Relationships, Life Changes

No matter how you feel after your treatments, talking with other people can help you handle the emotions you are having.

You are not alone in dealing with your cancer. Friends and family can learn how to support you during tough times. You can also talk to counselors and other cancer survivors.

It can be helpful to have someone to talk to, even if they can't solve all your problems.



Here are some ways you can help meet your emotional needs. Check the box next to the service you would like to learn more about.

- I want to meet other cancer survivors and hear their stories.
- I want to know where I can find emotional support.
- I want to know how I should talk to my friends and family about my cancer.
- □ I would like to talk to a professional about the feelings I am having.
- I would like my family to talk to a professional about the feelings they are having.
- I want to talk to someone my own age about my cancer.



# **Practical Concerns**

Money, Job, Resources

Your practical concerns may change as you finish treatment. You may have worries such as medical bills, child care expenses, food or transportation costs. These are some of the concerns other cancer survivors have.

# Do you have concerns about practical issues?



Make a check next to the things you would like help with or write down your own concerns.

# Money and Insurance

- I am having trouble paying for my medical expenses.
- □ I need help getting through the healthcare system.
- □ I'm not sure how to collect my medical benefits.

## Job

- □ I want my boss to understand my special needs as a cancer survivor.
- I am having difficulty finding work.

# **Finding Resources**

- □ I need help with my children.
- I am having trouble traveling to my medical appointments.

# Other

You can use modern medicine without turning your back on tradition and culture. I respected my traditional healing methods, used my culture and still used modern medicine to get through cancer.

- HollyAnna, cancer survivor

# **Practical Concerns**

Money, Job, Resources

As a cancer survivor, you are not alone. There may be resources in your community that can help you with your practical concerns. Talk to your healthcare provider or one of the resources in the back of this booklet to find the services you need.



Here are some services you might need. Check the box next to the service you would like to learn more about.

# **Money and Insurance**

- I would like a community health aid or navigator to help me through the system.
- □ I would like to know more about organizations that provide help with money issues.

# Job

- □ I want to make sure I am treated fairly at work.
- □ I want to know more about my legal rights.

# **Finding Resources**

- I would like help finding resources in my community.
- I would like to know how I can find transportation to my medical appointments.



# To learn more about these services, I can:

	Talk to a doctor, nurse or social worker. Reach out to other cancer survivors.		
Call one of the groups on the			
	following pages.		
	Research on the Internet or at the library.		
	<ul> <li>Reach out to members of my</li> </ul>		
	faith-based groups.		
	Talk to family and friends.		

Talk to your healthcare provider about the information you find.

# Plan for Your Next Steps

Now that you have checked off the physical, emotional and practical concerns you have, it is time to set a plan of action. Follow these steps to get the help you need.

- 1. Make sure you have gone through this booklet and checked off all the concerns you have.
- 2. Think about where you will look for help and support.
- Discuss the concerns you checked off in this booklet with your healthcare provider or someone on your healthcare team.
- **4.** Call the toll-free numbers on the following pages, or visit the websites to help you find the services you need.
- 5. Order a free LIVESTRONG notebook by filling out the form in the back of this booklet.

# Resources

These groups can help you with your physical and emotional needs. They can also help you with practical issues such as insurance and money matters.

# **American Pain Foundation**

Toll-free: 1.888.615.7246 www.painfoundation.org

The American Pain Foundation (APF) provides information and education about pain and pain management through free publications, a website, an online pain community, emails and tollfree calls. APF supports research and advocacy, bringing the voices of people with pain to healthcare providers and government agencies.

## LIVESTRONG Survivor Care

Toll-free: 1.866,235,7205 www.livestrong.org

LIVE**STRONG** Survivor*Care* will provide you with information, education, counseling services and referrals to other resources. You can also speak with a professional oncology social worker.

# **National Cancer Institute**

Toll-free: 1.800.4.CANCER (1.800.422.6237)

www.cancer.gov

You can speak with caring staff who can explain medical information in easy-to-understand terms. They answer calls in English and Spanish.

# National Hospice and Palliative Care Organization

Toll-free: 1.800.658.8898

www.nhpco.org

The National Hospice and Palliative Care Organization offers discussion groups, information about how to find a hospice and information about the financial aspects of hospice care. Staff also answer calls in Spanish.

# **Native American Cancer Research**

Toll-free: 1.800.537.8295

or go to the "tree" at www.NatAmCancer.org

Native American Cancer Research provides culturally relevant survivor support information, educational modules online and other services.

# **Patient Advocate Foundation**

Toll-free: 1.800.532.5274 www.patientadvocate.org

Patient Advocate Foundation can work with you to settle insurance, employment and debt matters resulting from your diagnosis. A case manager will work together with you, your healthcare provider and/or your employer to help with these issues.

# Support Groups

Contact these groups to help you find the support you need. Each of these groups can help you connect with other survivors and/or find emotional support in your area.

# **American Cancer Society**

Toll-free: 1.800.ACS.2345 (1.800.227.2345) www.cancer.org

An information specialist can answer your questions 24 hours a day, seven days a week. They can also help you find support groups in your area.

# The Leukemia & Lymphoma Society

Toll-free: 1.800.955.4572 www.leukemia-lymphoma.org

The Leukemia & Lymphoma Society has developed programs all over the country to meet the needs of patients, families and oncology professionals; the people who deal with blood cancer every day and the people who care for them.

# Gilda's Club® Worldwide

Toll-free: 1.888.GILDA.4.U (1.888.445.3248) www.gildasclub.org

Gilda's Club Worldwide provides free social and emotional support to men and women with cancer, their families and friends. There are Gilda's Clubs throughout the United States and Canada.

# **Native People's Circle of Hope**

Toll-free: 1.877.773.8248 www.nativepeoplescoh.org

Native People's Circle of Hope is a nonprofit coalition of Native cancer survivors and support groups. Native is defined as American Indian, Alaska Native, Hawaiian Native and other people indigenous to the United States.

# The Wellness Community

Toll-free: 1.888.793.WELL (1.888.793.9355) www.thewellnesscommunitv.ora

The Wellness Community provides free support groups, educational programs, exercise, nutrition and relaxation classes at 22 centers and 28 satellites across the United States and online for people with cancer and their loved ones.

# Are you interested in starting a support group in your area?

People Living Through Cancer, Inc. and the Indian Health Service sponsor a free, national week-long training for American Indians interested in developing cancer survivorship programs in their communities.

To learn more, call: People Living Through Cancer, Inc.

Toll-free: 1.888.441.4439

www.pltc.org

### List local resources here:

# **Notes**

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Lance Armstrong Foundation Attn: LIVE**STRONG**<sup>\*\*</sup> PO Box 161150 Austin, TX 78716-1150

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# The new LIVESTRONG" Survivorship Notebook is now available.



The LIVE**STRONG**<sup>®</sup> Survivorship Notebook can help you organize and guide your cancer experience. The easy-to-carry, three-ring binder contains information on:

- Physical, emotional and practical survivorship topics
- Stories of cancer survivors talking about experiences
- Survivorship tools to help you keep track of important information
- Sections for you to add your own records, notes, pamphlets and information

Because the Notebook is portable, you can take it with you to healthcare appointments and other important appointments.

To receive a free copy, please fill out the form on the back of this page and mail it to the Lance Armstrong Foundation (postage provided) or fax to 1.512.347.1582.





To receive a free copy of the LIVE**STRONG** Survivorship Notebook, please complete this form and mail it to the Lance Armstrong Foundation (postage provided) or fax to 1.512.347.1582.

NA/	ME					
MAI	LING ADDRESS					
CIT	Y	STA	ATE ZIP			
PHONE		EMA	AIL			
Ple	ase answer the following questions.					
Person with cancer is			Is the person with cancer			
	Myself		Male			
	Family member		Female			
	Spouse / Significant other					
	Friend					
	Other - please describe					
le t	he person with cancer	W/F	hat is the age of the person with cancer			
П	Newly diagnosed		0.14			
_	Currently in treatment					
	Finished with treatment					
	Long term	_				
_	(has been out of treatment for 5+ years)	_	65 and over			
П	Chronic	Ш	05 dila over			
_	(Taking medication for rest of life)					
	Recurrence					
(Cancer has come back or second cancer diagnosis)						
(Suited has come back of second current diagnosis)						
What best describes the ethnic background of the person with cancer						
	African American/Black		American Indian/Alaska Native			
	Asian		Caucasian/White			
	Hispanic/Latino		Native Hawaiian/Pacific Islander			
	Other		I prefer not to respond			
Do	you have					
	Private insurance coverage					
	Medicare	1	LIVESTRONG			
	Medicaid		RESOURCE FOR CANCER SURVIVORS			
	None		LANCE ARMSTRONG FOUNDATION			

www.livestrong.org 1.866.235.7205

Special thanks to the cancer survivors who made this brochure possible.

