

# 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:

- Go through this booklet and check off the physical, emotional and day-to-day 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 Concerns**

Pain, Body, Lifestyle

Now that you have finished treatment, you may have special needs in caring for your body. Ask your healthcare provider about these changes or what you can expect.

# Do you have concerns about changes in your body?



Make a check next to the things you 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.

# **Body Changes**

- I am not sure how the surgery, treatment or medicines I have taken or am taking will affect my body.
- My feelings about my body have changed.
- □ I feel tired often.
- □ I have trouble remembering things and my mind works more slowly than before.

# 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 Concerns:**

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

The cancer was just something to wake me up.

- Ilene, cancer survivor

# Physical Needs 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.

# Do you need help meeting your needs?



Check the box next to the services or information you need.

# **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 to know more about how my treatment may have affected my fertility.

# 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 Concerns**

Feelings, Relationships, Life Changes

Now that you have finished treatment, 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.
<ul> <li>Relationships</li> <li>I am not sure how to talk to my friends and family about my cancer.</li> <li>I am not sure how to talk to my children about my cancer.</li> </ul>
<ul> <li>Life Changes</li> <li>The things that are important to me have changed.</li> <li>My cancer has changed my spirituality.</li> <li>I don't know what to expect.</li> </ul>
Other Concerns:

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 Needs**

Feelings, Relationships, Life Changes

No matter how you feel after your treatment, 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 cannot solve all your problems.

# Do you need help meeting your needs? Check the box next to the services or information you need. 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.



# Day-to-Day Concerns

Money, Job, Resources

Your day-to-day concerns may change now that you have finished 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 day-to-day concerns? 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 am 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 a hard time finding or returning to work. **Finding Resources** □ I need help with my children. ☐ I am having trouble traveling to my follow-up care appointments. Other Concerns:

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

# **Day-to-Day Needs** Money, Job, Resources

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

# Do you need help meeting your needs?



Check the box next to the services or information you need.

# **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.  Reach out to members of my 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 day-to-day 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.

# Resources

These groups can help you with your physical and emotional needs. They can also help you with day-to-day 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 toll-free calls. APF supports research and advocacy, bringing the voices of people with pain to healthcare providers and government agencies.

# The LIVE**STRONG** Foundation

Toll-free: 1.855.220.7777

www.LIVESTRONG.org/GetHelp

The LIVE**STRONG** Foundation will provide you, your family, friends and caregivers with support, as well as education on treatment options and fertility preservation. Additionally, insurance, employment and financial matters can be addressed through referrals to financial and local resources. Ask for a free LIVE**STRONG** Guidebook. It provides important information and tools to support you through your cancer journey. You can call the LIVE**STRONG** Foundation Monday—Friday, 9am—5pm CST.

## **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.

# **Caring Connections**

Toll-free: 1.800.658.8898

www.caringinfo.org

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO) will provide you with resources and information to help you make decisions about end-of-life and services. Staff also answers 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:

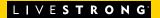
# **Notes**

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THE LIVE**STRONG** FOUNDATION
SERVES PEOPLE AFFECTED BY
CANCER AND EMPOWERS THEM TO
TAKE ACTION AGAINST THE WORLD'S
LEADING CAUSE OF DEATH.

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



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