

Resources Compendium for Patient Navigators
Assisting Cancer Survivors After Treatment



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- Inclusion of content in this compendium is intended to guide Patient Navigators to resources and organizations that may be helpful to the patients and survivors they assist. Inclusion does not suggest endorsement.
- There are hyperlinks directly to the resources embedded in the resource title for quick access.
- Some, but not all resources included in this compendium are available in hard copy in addition to availability online from the sponsoring organization. Contact each organization to find out.
- Contact each organization to learn about updates or changes to the included resources below.
- Learn about the American Cancer Society from www.cancer.org and the George Washington University Cancer Institute from www.gwcancerinstitute.org.

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Late and Long -Term Effects¹ of Cancer and Cancer Treatment Resources

Aftereffects of Cancer Treatment

Live**STRONG**

www.livestrong.org 866-673-7205

*Live**STRONG** provides information about aftereffects – the physical, emotional and practical changes that happen after cancer treatment has been completed. Knowing what some of the common aftereffects are and why they happen can help survivors prepare for life after treatment.*

Late Effects

American Society of Clinical Oncology

www.asco.org 571-483-1300

The American Society of Clinical Oncology provides information approved by its editorial board on the types of late effects, screening for late effects, long-term follow-up care, and questions that survivors can ask the doctor about late effects.

Aftereffects of Chemotherapy Drugs

Chemocare.com

Chemocare.com provides many types of information on the aftereffects of specific chemotherapy drugs as well as how to manage these effects. This website allows you to search by the chemical name of the drug, brand name of the drug, or the acronym that is most commonly used for the drug. Information includes long-term drug effects on the body, suggestions on when to contact your health care provider and self-care tips. Information on the site is also available in Spanish.

Post-Treatment Survivor Resources

CancerCare

www.cancer.org 1-800-813-HOPE (4673)

CancerCare offers the supportive services for survivors post-treatment and their loved ones. Services are free and provided in both English and Spanish. Services include counseling, support groups, education workshops, publications, and limited financial assistance.

Ways to Manage Physical Changes

Facing Forward: Life After Cancer Treatment

National Cancer Institute

www.cancer.gov 800-422-6237 (800-4-CANCER)

As part of the Facing Forward: Life After Cancer Treatment, the National Cancer Institute provides information to cancer survivors about ways to manage physical changes and describes some of the problems that can occur when treatment is over.

¹ The terms 'side effects' 'aftereffects' and 'late and long-term effects' generally have similar meaning and generally refer to side effects experienced by a person as a result of cancer and its treatments.

[Aftereffects of Cancer Treatment for Survivors of Childhood and Adolescent Cancers](#)

CureSearch

www.curesearch.org 1-800-458-6223

The CureSearch website provides information on aftereffects of cancer treatment for survivors of childhood and adolescent cancers. Although the information is written about children and adolescents, adults may find some of the information useful in understanding the possible aftereffects of cancer. Information for caregivers is also included. The website provides guidelines for post-treatment screenings, explains possible aftereffects caused by cancer treatment and lists tips to manage aftereffect symptoms.

[Long-Term and Late Effects of Blood Cancers](#)

The Leukemia & Lymphoma Society

www.lls.org 800-955-4572

The Leukemia & Lymphoma Society provides specific information about the possible long-term and late effects that blood cancer survivors may experience, and tips to manage the effects to keep them at bay.

[Getting Help Series for ACS Navigators \(order them internally from ACS only\)](#)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

The American Cancer Society can provide its navigators with helpful one-page summaries of important topics to cancer patients and survivors. Several are available in Spanish and Creole.

Tearsheet Title & Number	First Published	Spanish	Creole
GHF Mouth Sores – 2132.00	Feb 2009	Yes – 2141.00	Yes
GHF Sleep Problems – 2131.00	May 2009	Yes – 2142.00	Yes
GHF Diarrhea – 2130.00	May 2009	Yes – 2140.00	Yes
GHF Cancer Pain – 2133.00	July 2009		
Being a Caregiver – 2134.00	Aug 2009		
GHF Nausea and Vomiting – 2136.00	Oct 2009		
When Cancer Comes Back – 2137.00	Oct 2009		
GHF Chemo Brain – 2139.00	Jan 2011		
GHF Fatigue – 2138.00	Jan 2011		
GHF Skin Changes – 2143.00	Feb 2011		

Financial Resources

Cancer Legal Resource Center

www.disabilityrightslegalcenter.org 1-866-THE CLRC (1-866-843-2572) or 212-736-1455

The Cancer Legal Resource Center (CLRC) provides information and resources on cancer-related legal issues to survivors, their families, friends, employers, health care professionals, and others coping with cancer. The CLRC offers information on a broad range of cancer-related legal issues, including health insurance, employment, government benefits, estate planning, advanced health care directives, family law and consumer assistance. Through a national toll-free Telephone Assistance Line (866-THE-CLRC), callers can receive information about relevant laws and resources for their particular situation. The CLRC volunteer panel of attorneys and other professionals provide more in-depth information and counsel to CLRC callers. All CLRC services are free and confidential. Services are available in both English and Spanish.

The National State Health Insurance Assistance Programs (SHIP) Resource Center

<https://shiptalk.org/>

SHIPs provide free one-on-one counseling and assistance via telephone and face-to-face interactive sessions to people with Medicare and their families. The website includes links to the SHIP in your state.

Patient Advocate Foundation

www.patientadvocate.org/ 800-532-5274

The Patient Advocate Foundation provides effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

Cancer and Careers

www.cancerandcareers.org/

Cancer and Careers is dedicated to empowering and educating people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events.

Job Accommodation Network

<http://askjan.org/> 800-526-7234

The Job Accommodation Network website has tools to help understand the types of workplace adjustments that may help to continue working during and after cancer treatment. The American Disabilities Act (ADA) is described in detail. Examples of worksite modifications and self-employment information are also provided.

HealthWell Foundation

<http://healthwellfoundation.org/> 800-675-8416

The HealthWell Foundation is a non-profit organization committed to addressing the needs of individuals with insurance who cannot afford their copayments, coinsurance, and premiums for important medical treatments.

Patient Services Inc.

www.patientservicesinc.org/ 800-366-7741

Patient Services evaluates an individual's financial, medical, and insurance situation to determine who is eligible for premium or co-payment assistance. Patient Services Representatives can walk through the online application process as well as mail appropriate forms and informative literature.

[Working During and After Treatment](#)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Whether a survivor is planning on continuing to work during cancer treatment or returning to work once treatment is completed, information from ACS can help survivors know what to expect.

[Catholic Charities](#)

<http://www.catholiccharitiesusa.org/NetCommunity/> 703-549-1390

In your local area, Catholic Charities may provide financial assistance to individuals who meet income guidelines and they may have local programs for assisting with utility payments.

[Salvation Army](#)

http://www.salvationarmyusa.org/usn/www_usn_2.nsf

In your local area, Salvation Army may provide financial assistance to individuals who meet income guidelines and they may have local programs for assisting with utility payments.

[LIVESTRONG](#)

www.livestrong.org 866-673-7205

*Among other resources, **LIVESTRONG** provides information and resources on financial and government assistance programs, health insurance, and legal and workplace issues of interest to survivors and their caregivers.*

[Leukemia & Lymphoma Society](#)

The Leukemia & Lymphoma Society

www.lls.org 800-955-4572

The Leukemia & Lymphoma Society provides guidance, support and resources to help patients and survivors address financial health issues. These include the Patient Financial Aid Program, Co-Pay Assistance Program, and information about insurance and employment. LLS Information Specialists are available by telephone, chat or email to provide assistance.

[Fear of Recurrence Resources](#)

[Living with Uncertainty: The Fear of Cancer Recurrence](#)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Most cancer survivors are concerned about their cancer coming back. The fear of recurrence is a normal fear. ACS addresses some common questions and concerns people may have when thinking about their cancer returning.

When Cancer Comes Back: Cancer Recurrence

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Cancer recurrence is a return of the cancer after a period of time in which no cancer could be detected. The odds of a cancer recurring depend on many factors, including the type of cancer and its extent within the body at the time of treatment. ACS provides answers to common questions about cancer recurrence.

American Psychological Oncology Society

www.apos-society.org 866-276-7443

Provides a toll-free help-line to patients and their caregivers can be referred to help them find psychological resources in their community.

Your Feelings

Facing Forward: Life After Cancer Treatment

National Cancer Institute

www.cancer.gov 800-422-6237 (800-4-CANCER)

As part of the Facing Forward: Life After Cancer Treatment, the National Cancer Institute provides information to cancer survivors about the range of emotions that survivors may experience and offers strategies to assist them.

Imerman Angels

www.imermanangels.org/

Imerman Angels carefully matches and individually pairs a person touched by cancer (a cancer fighter or survivor) with someone who has fought and survived the same type of cancer. These 1-on-1 relationships inspire hope and offer the chance to ask personal questions and receive support from someone who is uniquely familiar with the experience. The service is absolutely free and helps anyone touched by any type of cancer, at any cancer stage level, at any age, living anywhere in the world.

National Coalition for Cancer Survivorship Cancer Survival Toolbox

National Coalition for Cancer Survivorship

<http://www.canceradvocacy.org/> 888-650-9127

NCCS provides a free, self-learning audio program to help people develop important skills to better meet and understand the challenges of their illness. The program contains a set of basic skills to help navigate a diagnosis and special topics on key issues faced by people with cancer. In a section titled, Living Beyond Cancer, a number of important issues that are specific to life beyond the diagnosis and initial treatment of cancer are discussed and includes the emotional aspects of cancer.

Fear of Recurrence

LIVESTRONG

www.livestrong.org 866-673-7205

Fear of recurrence is the experience of worry and concern that cancer might come back. It affects each survivor differently. Understanding how to manage fear of recurrence can help survivors feel more confident and secure about survivorship.

After Treatment Ends: Tools for the Adult Survivor

CancerCare

www.cancercare.org 1-800-813-HOPE (4673)

A booklet produced in 2010 that includes information and resources to address emotional concerns, including fear of recurrence.

Emotional Health & WellBeing

Cancer Support Community

www.thewellnesscommunity.org 202-659-9709

From the Cancer Support Community you will read about the common feelings that cancer survivors experience after treatment, and learn to recognize when they need support with emotional issues.

Nutrition Resources

Nutrition for People with Cancer

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Nutrition is an important part of cancer treatment. Eating the right kinds of foods during and after treatment can help survivors feel better and stay stronger. Learn more about the importance of good nutrition during and after cancer treatment.

Nutrition After Treatment Ends – Tips for Eating Healthy After Cancer

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

As survivors begin to feel better, they may have questions about eating a healthy diet. Eating well will help survivors regain strength, rebuild tissue, and feel better overall.

Eat Healthy - Be Healthy After Treatment

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Good health starts with good nutrition. Find tips and recipes to help make healthy food choices.

American Cancer Society's Dietitian on Call Program (In limited service areas and by telephone only)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Provides survivors, their caregivers and health care professionals with information and support regarding nutrition-related issues. Registered dietitians provide free nutrition counseling and assistance with nutrition-related questions.

Eating Hints for Cancer Patients Before, During & After Treatment

National Cancer Institute

www.cancer.gov 800-422-6237 (800-4-CANCER)

Survivors can use this book before, during, and after cancer treatment. It has hints about common types of eating problems and ways to manage them.

[Nutrition for Wellness](#)

Cancer Support Community

www.thewellnesscommunity.org 202-659-9709

The Cancer Support Community provides guidance on eating the right kinds of foods before, during, and after treatment to feel better and stay stronger. The nutritional information provided represents a composite of the current research and recommendations for good overall health.

[Nutrition After Cancer Treatment](#)

American Institute for Cancer Research

www.aicr.org 800-843-8114

American Institute for Cancer Research provides a nutrition hotline, healthy recipes for survivors, and the Food for the Fight online video/DVD featuring personal accounts and cooking demonstrations that provide cancer survivors and caregivers with the information they need about diet and cancer after treatment.

[Food and Nutrition for Blood Cancer Survivors](#)

The Leukemia & Lymphoma Society

www.lls.org 800-955-4572

The Leukemia & Lymphoma Society provides helpful information and tips for survivors.

Physical Activity Resources

[Get Active - Be Healthy After Treatment](#)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

Being active is an important part of staying healthy, regardless of age. It may also lower risk for certain types of cancer. Get suggestions to help get and stay active.

[LIVESTRONG at the YMCA](#)

LIVESTRONG

www.livestrong.org 866-673-7205

***LIVESTRONG** at the YMCA is a twelve-week, small group program designed for adult cancer survivors. This program fulfills the important need of supporting the increasing number of cancer survivors who find themselves in the transitional period between completing their cancer treatment and the shift to feeling physically and emotionally strong enough to attempt to return to their normal life or their "new normal". The program is conducted outside of medical facilities to emphasize that **LIVESTRONG** at the YMCA is about health, not disease.*

[Physical Activity: Suggestions and Tips](#)

American Society of Clinical Oncology

www.asco.org 888-651-3038

Regular physical activity not only helps lower risk of cancer, but it may also improve quality of life, mood, and other side effects of cancer and cancer treatment for people with cancer and cancer survivors.

[Physical Activity and Weight Management Guidelines for Cancer Survivors](#)

American Institute for Cancer Research

www.aicr.org 800-843-8114

American Institute for Cancer Research provides physical activity and healthy weight management guidelines and tips for cancer survivors.

[Survivorship Care Planning Resources](#)

[Survivorship Care Plans](#)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

American Cancer Society provides links to several cancer survivorship care planning tools and resources.

[Journey Forward](#)

www.journeyforward.org 707-636-5900

The Journey Forward program deals with the need for survivors and their doctors to work as a team after active treatment comes to an end.

[LIVESTRONG Care Plan](#)

LIVESTRONG

www.livestrong.org 866-673-7205

This free online tool was created to help survivors develop a personalized plan for post-treatment care. It can help survivors work with their oncologist and primary health care provider to address medical, emotional and social challenges that may arise after cancer treatment is completed. By answering some questions related to cancer treatment, survivors will receive information about their follow-up care. This information includes symptoms to watch for in the future and steps to take to stay healthy.

[Getting Follow-up Medical Care](#)

[Facing Forward: Life After Cancer Treatment](#)

National Cancer Institute

www.cancer.gov 800-422-6237 (800-4-CANCER)

As part of the Facing Forward: Life After Cancer Treatment, the National Cancer Institute provides information to cancer survivors about knowing what to expect after cancer treatment, lifestyle changes, and important decisions they may need to make.

[Follow-up Care After Treatment](#)

National Cancer Institute

www.cancer.gov 800-422-6237 (800-4-CANCER)

The National Cancer Institute provides key points and frequently asked questions regarding follow-up care post-treatment, as well as links to the existing organizations that offer follow-up guidelines.

[Keeping Follow-Up Appointments](#)

The Leukemia & Lymphoma Society

www.lls.org 800-955-4572

The Leukemia & Lymphoma Society provides information to survivors about the importance of follow-up care and what that might entail for survivors of blood cancers.

Resources for Adolescents and Young Adults with Cancer

[Aftereffects of Cancer Treatment for Survivors of Childhood and Adolescent Cancers](#)

CureSearch

www.curesearch.org 800-458-6223

The CureSearch website provides information on aftereffects of cancer treatment for survivors of childhood and adolescent cancers. Although the information is written about children and adolescents, adults may find some of the information useful in understanding the possible aftereffects of cancer. Information for caregivers is also included. The website provides guidelines for post-treatment screenings, explains possible aftereffects caused by cancer treatment and lists tips to manage aftereffect symptoms.

[Life After Treatment – Cancer in Young Adults](#)

American Society of Clinical Oncology

www.asco.org 571-483-1300

The American Society of Clinical Oncology provides information specifically for young adults on what it means to be a cancer survivor, including managing health, coping after cancer, and returning to school or work after cancer.

[Cancer in Teens: Life After Treatment](#)

American Society of Clinical Oncology

www.asco.org 571-483-1300

Finishing cancer treatment is a great feeling, but what happens next can be confusing for teens. Information from ASCO can help teens adjust to life after cancer treatment.

[LIVESTRONG: A Podcast Series for Young Adults with Cancer](#)

LIVESTRONG

www.livestrong.org 866-673-7205

***LIVESTRONG:** A Podcast Series for Young Adults with Cancer provides firsthand accounts from other adolescent and young adult cancer survivors as they share their experiences and advice about a wide variety of cancer-related issues and concerns. Each video is 5–7 minutes long and relays important information about common physical, emotional and practical concerns. Shared through the experiences and insight of adolescent and young adult cancer survivors, every topic addresses the unique needs of young adults with cancer. Many topics also include a list of action items that survivors can consider to address their concerns, as well as a list of cancer-related organizations survivors can contact for additional support.*

[Planet Cancer](#)

<http://myplanet.planetcancer.org/>

Planet Cancer is a community of young adults with cancer in their 20s and 30s. A place to share insights, explore fear and have some laughs with others who get it.

[Post-Treatment – Breast Cancer in Young Women](#)

Young Survival Coalition

<http://www.youngsurvival.org/>

Women surviving breast cancer sometimes describe the first few months after treatment as a time of change and anxiety. But they also often say that life takes on new meaning and that they arrive at new and important understandings. That might mean changing diet, activities and sources of support. This webpage offers tips for post-treatment life, including making the most of follow-up care, understanding family history and finding resources and support through Young Survival Coalition.

[Teens and Young Adults – Blood Cancers](#)

The Leukemia & Lymphoma Society

www.lls.org 800-955-4572

The Leukemia & Lymphoma Society offers information specific to the 18-39 population and YAconnect: Straight Talk for Young Adults Facing Cancer, which features programs and support for young adults aged 18 to 39 who are facing cancer via online, discussion board and webcasts.

Resources for Children of Parents or a Loved One with Cancer

[For Children and Families from CancerCare](#)

CancerCare

www.cancercare.org 1-800-813-HOPE (4673)

Children and teens who are affected by cancer have special needs and concerns. CancerCare offers free, professional services to help support the particular needs of children and parents. Services include counseling, support groups, education workshops, publications, and limited financial assistance.

[Helping Children and Teens Understand When a Parent or Loved One has Cancer](#)

CancerCare

www.cancercare.org 1-800-813-HOPE (4673)

CancerCare offers a free, on-demand, hour-long podcast with a panel of four experts that discuss important topics including: common questions kids ask, needs of kids whose parent has cancer, and tools to help kids and teens cope. The content is presented for adults to help inform their communications with children and teens.

[Camps and Retreats for Families and Children Touched by Cancer](#)

Compiled by American Society of Clinical Oncology

www.asco.org 571-483-1300

Summer camps, week-long retreats, or weekend gatherings can be a wonderful way for children, adults, and families to come together to experience new adventures, find support, and learn something new about themselves. This list compiled by ASCO offers just some of the thousands of national and international camps and retreats available during the coming year.

Resources for Parents with Cancer

[Tips for Talking with Your Children About Cancer](#)

The Mayo Clinic

www.mayoclinic.com

A blog post from the Mayo Clinic provides a summary of tips that adults can use when talking with children about cancer.

[Camps and Retreats for Families and Children Touched by Cancer](#)

Compiled by American Society of Clinical Oncology

www.asco.org 571-483-1300

Summer camps, week-long retreats, or weekend gatherings can be a wonderful way for children, adults, and families to come together to experience new adventures, find support, and learn something new about themselves. This list compiled by ASCO offers just some of the thousands of national and international camps and retreats available during the coming year.

Resources for Parents of Children with Cancer

[Childhood Cancer: Late Effects of Cancer Treatment](#)

American Cancer Society

www.cancer.org 800-227-2345 (800-ACS-2345)

The American Cancer Society provides information about the causes of late effects of cancer treatment, who is at risk and the treatment effects on specific parts of the body.

[How a Child Understands Cancer \(English and Spanish\)](#)

American Society of Clinical Oncology

www.asco.org 571-483-1300

American Society of Clinical Oncology offers information and guidance for parents on how and what to share with children about their child's cancer by age groups.

[Late Effects of Childhood Cancer, Parts I and II \(English and Spanish\)](#)

American Society of Clinical Oncology

www.asco.org 571-483-1300

American Society of Clinical Oncology offers two videos about the late effects of childhood cancer. Information about the risks of late effects, how to minimize them, symptoms to watch for and more are detailed.

Cancer in Children

American Society of Clinical Oncology

www.asco.org 571-483-1300

American Society of Clinical Oncology offers links to helpful resources related to cancer in children.

For Parents and Families from CureSearch

CureSearch

www.curesearch.org 800-458-6223

Getting beyond cancer treatment involves a focus on wellness and ways to improve quality of life. Discover ways to maintain a healthy lifestyle, signs to look for, potential risks and ways to celebrate the life of a child with cancer.

Aftereffects of Cancer Treatment for Survivors of Childhood and Adolescent Cancers

CureSearch

www.curesearch.org 800-458-6223

The CureSearch website provides information on aftereffects of cancer treatment for survivors of childhood and adolescent cancers. Although the information is written about children and adolescents, adults may find some of the information useful in understanding the possible aftereffects of cancer. Information for caregivers is also included. The website provides guidelines for post-treatment screenings, explains possible aftereffects caused by cancer treatment and lists tips to manage aftereffect symptoms.

Late Effects of Treatment for Childhood Cancer

National Cancer Institute

www.cancer.gov 800-422-6237 (800-4-CANCER)

The National Cancer Institute provides information on monitoring for late effects of childhood cancer treatments and resources to support survivor care.

Childhood Cancer Survivors of Blood Cancers

The Leukemia & Lymphoma Society

www.lls.org 800-955-4572

The Leukemia & Lymphoma Society provides information to caregivers about the possible long-term and late health effects of blood cancers and treatments, and guidance about follow-up care.

Camps and Retreats for Families and Children Touched by Cancer

Compiled by American Society of Clinical Oncology

www.asco.org 571-483-1300

Summer camps, week-long retreats, or weekend gatherings can be a wonderful way for children, adults, and families to come together to experience new adventures, find support, and learn something new about themselves. This list compiled by ASCO offers just some of the thousands of national and international camps and retreats available during the coming year.

Matrix of Organizations and Resources

	<i>Late and Long-Term Effects</i>	<i>Financial</i>	<i>Fear of Recurrence</i>	<i>Nutrition</i>	<i>Physical Activity</i>	<i>Care Planning</i>	<i>Adolescents and Young Adults</i>	<i>Children of Loved One with Cancer</i>	<i>Parents with Cancer</i>	<i>Parents of Children with Cancer</i>
American Cancer Society	X	X	X	X	X	X				X
American Institute for Cancer Research				X	X					
American Psychological Oncology Society			X							
American Society of Clinical Oncology/cancer.net	X				X	X		X	X	X
Cancer and Careers		X								
CancerCare	X		X				X	X	X	
Cancer Legal Resource Center		X								
Cancer Support Community			X	X						
Catholic Charities		X								
Chemocare.com	X									
CureSearch	X									X
Healthwell Foundation		X								
Imerman Angels			X				X			
Job Accommodation Network		X								
Journey Forward						X				
Leukemia & Lymphoma Society	X	X		X		X	X			X
LIVESTRONG	X		X		X	X	X			
Mayo Clinic									X	
National Cancer Institute	X		X			X				X

National Coalition for Cancer Survivorship			X							
National State Health Insurance Assistance Program		X								
Patient Advocate Foundation		X								
Patient Services, Inc.		X								
Planet Cancer						X				
Salvation Army		X								
Young Survival Coalition						X				

