

CHILDHOOD CANCER SURVIVORSHIP: AN OVERVIEW FOR SOCIAL WORKERS



INTRODUCTION

While advances in detection and treatment of childhood cancers are helping thousands of children live longer, the short- and long-term effects of cancer have an impact on an individual's life from every standpoint — physically, psychologically, educationally, cognitively, vocationally, spiritually, socially and financially.

This brochure will:

- Provide a basic understanding of childhood cancer survivorship needs and effects on individuals;
- Raise awareness and sensitivity about such survivorship and its inherent needs; and
- Identify practical tips and resources that social workers can encourage survivors to utilize.

CANCER BASICS

Despite dramatically increased survival rates for certain types of childhood cancer, it is still the leading cause of death by disease in children. Each year, about 12,400 children are diagnosed with cancer and 2,300 die. The majority of children diagnosed with cancer are survivors.

Though patient advocacy groups consider all children with a cancer diagnosis to be survivors from the *day of diagnosis*, national survival statistics generally reflect the number of children surviving at least five years from diagnosis. Today, there are more than 270,000 pediatric cancer survivors in the United States (*Childhood Cancer Survivorship: Improving Care and Quality of Life*, IOM, 2003).

There are many different types of childhood cancer each with a different outcome. The most common childhood cancers include brain tumors and hematologic (blood)

cancers such as leukemia and lymphoma. Common treatments include chemotherapy, radiation and surgery.

CONCERNS DURING TREATMENT

Health concerns during treatment vary depending on the age of the child. The majority of children continue in school throughout their treatment but some, due to the complications or nature of the disease/treatment, will miss months or even a whole year of school attendance and must be taught at home.

When in treatment, a child's health care team will usually include a pediatric oncology social worker. The pediatric oncology social worker will be a valuable resource in determining (with the family) any special accommodations that may be necessary for school re-entry when treatment is completed.

Latency age children (ages 6-12) are likely to be focused on avoiding pain and discomfort associated with the treatments, spending time with friends and keeping up with as much of their normal routine as possible. Managing the physical and social aspects of school are important as students may be self-conscious about their looks or abilities, or may have trouble concentrating if they don't feel well.

Adolescents (ages 13-19) are old enough to understand the severity of a cancer diagnosis and likely to pick up on their parents' anxieties and worries as well. They may or may not express concerns about dying, but they likely have them even if unexpressed. They tend to be more aware of how disruptive the cancer and treatments are to their and their families' lives and how the treatment demands interfere

with their normal attempts to individuate from parents at this time. These teens are concerned about maintaining social connections, but also may withdraw out of self-consciousness or sheer side effects that limit their capacity to participate in activities.

CONCERNS AFTER TREATMENT

Physical Effects of Childhood Cancer

The presence and extent of long-term treatment effects depend on the diagnosis and type of treatment the child received, as well as the age and developmental stage of the child during treatment. The availability of social support — along with individual and family factors — also influences the long-term impact of the childhood cancer diagnosis.

Some of the more common late and long-term physical effects include:

- **Heart-** Certain chemotherapy drugs as well as radiation to the chest or spine can affect the heart muscle in some patients. This is more likely to happen with higher doses of these chemotherapy agents or with the combination of the drugs and radiation. In addition, younger children treated prior to completion of growth are more at risk. These children need to have periodic heart function tests to monitor any changes and may also need to be followed by a cardiologist.
- **Lungs-** Once again, certain chemotherapy drugs, as well as radiation to the lungs, chest or spine, can damage the lungs. This is also more likely to occur with the combination of these chemotherapy drugs and radiation. Problems that can develop include scarring, repeated infections, or restrictive/obstructive lung disease. It is important for children to have their lung function tested once they are at least two years from therapy. If symptoms such as exercise intolerance, shortness of breath, chest pain or frequent lung infections are found, additional follow-up with a lung specialist is recommended.
- **Kidneys-** Radiation to the kidneys or any areas that included the kidneys (such as the abdomen or spine) may lead to kidney damage. In addition, certain chemotherapy drugs and a few specific antibiotics may also cause kidney damage. Children who had surgical removal of one kidney may be at increased risk for these problems as well. Children with these therapies should have a regular physical exam, blood pressure



monitoring, blood work and urine testing to measure kidney function. It is important that these children always drink plenty of water, especially during hot weather.

- **Thyroid-** Radiation to any areas of the head or neck can lead to a non-functioning thyroid gland and hypothyroidism. This affects growth and metabolism as well as other body functions. Children at risk for thyroid problems should have their thyroid hormone levels checked regularly. Low levels can be treated easily with oral medication.
- **Hearing-** Certain chemotherapy drugs as well as radiation to the brain are known to cause hearing loss in some individuals. In addition, these individuals may have received specific antibiotics during their course of treatment that can also contribute to hearing loss. The loss is permanent and can range from mild to high frequency hearing loss to severe, requiring the use of hearing aids. Children at risk for hearing loss need to have periodic hearing evaluations by an audiologist.
- **Dental-** Chemotherapy before permanent teeth are formed can lead to an increased risk for cavities as well as impair tooth development. Additionally, radiation therapy that includes the mouth and/or salivary glands may also place the child at an increased risk for dental problems. It is important that these children maintain good oral hygiene and have regular follow-up visits with a dentist.

- **Growth-** Treatment for childhood cancer, especially radiation therapy to the brain and/or spinal cord, can impair growth. Children who were treated with radiation for a brain tumor or were treated before puberty are most at risk. However, radiation to the brain may also be used to treat other types of cancers, including some types of leukemia. These children should be followed regularly to measure their height and weight. In some cases, specialized testing or treatments such as growth hormone therapy may be recommended.
- **Fertility-** Certain chemotherapy drugs and radiation to the testes or ovaries can lead to delayed puberty, infertility or early menopause. This again depends on the dose of the chemotherapy or radiation and the age of the child and their pubertal status at the time of treatment. Regular medical follow-up and monitoring of certain hormone levels can help determine if these problems are occurring. However, young adults at risk for infertility should be counseled regarding use of birth control until the status of their fertility is known. (See below for more information.)
- **Secondary malignancies-** The diagnosis of cancer at any age automatically brings an increased risk of developing a second (different) malignancy. Coupled with that, many chemotherapy drugs as well as radiation therapy are associated with an increased risk of developing secondary malignancies such as leukemia, breast cancer, skin cancer or other types of adult cancers. Regular medical follow-up, awareness of symptoms to look for and following American Cancer Society guidelines for cancer screening (www.cancer.org) are even more important for the cancer survivor.
- **Cognitive effects-** Treatment for childhood cancer, including radiation to the brain and certain types of chemotherapy drugs, can put children at risk for developing cognitive difficulties. The extent of the cognitive problems depends on the age of the child during treatment, the amount of radiation and/or chemotherapy given, and the duration of treatment. Survivors may experience cognitive and behavioral changes years after treatment ends. When difficulties begin, the individuals often do not connect the problem to their cancer treatment. They may experience memory changes that have an impact on the way they remember, learn and think.



TIPS FOR SOCIAL WORKERS TO INCLUDE IN A COGNITIVE ASSESSMENT

A social worker working with an individual who is a childhood cancer survivor should include the following potential cognitive problem areas in their assessment:

- Review of academic history, needs and performance, including any noticeable changes in grades;
- Difficulty with work mastered previously or in remembering what has been read;
- Excessive time to complete homework;
- Attention and concentration issues;
- Poor social skills and lower social maturity;
- Poor frustration tolerance;
- Difficulty in math, reading, or spelling; and
- Poor skill mastery – i.e., tying shoes, riding a bike, jumping rope, coloring within the lines

If the survivor is experiencing changes or having difficulty in these areas, she or he should be referred for a neuropsychological evaluation and testing to assess the extent of the cognitive effects of cancer.

PSYCHOSOCIAL EFFECTS OF CHILDHOOD CANCER

The emotional impact of surviving childhood cancer is complex. Initially, young people are relieved and even elated to complete their treatment course and get the reassuring news at follow-up medical center visits that they seem to be cured of cancer and can resume a “normal” life. Although returning to pre-cancer normal is unlikely, young survivors can learn to create a new sense of normalcy that incorporates their memories and particular childhood cancer experience.

Common psychological and social effects of childhood cancer include:

- **Redefining family relationships-** In some ways *all members of the family are survivors* of the cancer experience, not just the person who is ill. Siblings and parents are also forever changed by the experience and have to find ways to manage all the feelings and adjustments imposed upon them by the cancer treatment process. Their sense of safety, control, and predictability about the world is affected by the cancer experience.

All the members of the family need to redefine their relationships with each other throughout and after the child's treatment. This is certainly true for the child who had cancer. At diagnosis, his/her role shifts to that of "sick child" with the attendant extra special attention, loosening of limits/expectations, and having little control or say over what others do to one's body. Siblings often experience a combination of jealousy, resentment, abandonment, anger, and guilt during the course of the survivor's treatment, and if unaddressed, for years afterwards.

- **Disrupted social development and losing friends-** The degree to which the survivor's social development is disrupted by the cancer depends on the age at diagnosis and treatment. A cancer diagnosis in adolescence is more likely to disrupt a survivor's social development, because peer relationships are so central to this stage of development. If the type of treatment causes physical disfigurement, cognitive limitations, or other noticeable disabilities (e.g., hearing or vision loss), there will be a greater impact on the survivor's social adjustment since body image, self-perception, and "fitting in" with peers are keenly tied to teenagers' feeling confident in social situations. Cognitive limitations, such as slower processing speed,

not only affect a survivor's learning, but may make it more difficult to keep up with a conversation, understand humor, or follow a train of thought.

- **Feeling "out of sync" with peers-** This reaction may result from the fact that survivors have faced very sophisticated life and death issues at early developmental stages, leading to a level of maturity beyond same-aged peers. Some survivors express this as frustration and impatience with their peers' focusing on (what seem to the survivor as) trivial problems like having the right clothes.

This, however, can be contrasted with a lack of maturity compared to peers, stemming from the fact that an adolescent under treatment will necessarily miss out on the sheer volume of opportunities to practice social interactions due to side effects and hospitalizations. In this case, a survivor may feel awkward and "behind" in their experience of dating or keeping up with the conversation in a group setting.

- **Risk-taking behaviors-** Some adolescent survivors can feel different from their peers in their degree of risk-taking behaviors. In particular, a subset of survivors engage in a high level of risk-taking activities such as alcohol/substance use, smoking (which in a cancer survivor poses much greater health risks than in the general population), or weight lifting that could damage their heart after certain types of chemotherapy treatment. In these cases, the survivor almost seems to understand their cancer experience as proof of the invincibility most adolescents imagine. On the other extreme, some survivors remain hyper-vigilant about their health and become overly cautious in their activities, circumscribing their lifestyle or becoming easily anxious about serious illness in the face of minor symptoms.



- **Fear about recurrence and late effects (e.g., fertility)-**

Every cancer survivor knows that once you have a diagnosis of cancer, your likelihood of recurrence naturally increases. Living with this thought and anxiety about recurrence or late effects of treatment can be difficult for most survivors to manage. Some survivors deal with it through denial, by not keeping medical follow-up appointments, and using negative coping skills such as substance use or abuse. Again, survivors who have a strong support system and who keep medical follow-up appointments are likely to have more accurate information and support in dealing with their long term effects and managing their anxiety or concerns.

- **Dealing with feelings and reactions-**

Children who survive cancer on a daily and long-term basis experience emotions ranging from anger, sadness, depression, anxiety, joy, hope, happiness, and gratitude. The resilience of children is truly remarkable, but all children will experience natural emotional responses to their illness, treatment, and long-term effects. Helping survivors cope and manage their feelings is important as a constructive outlet for support and guidance in dealing with their needs. Sometimes, professional help is needed to cope with mental health needs including adjustment needs as one manages illness and its effects.

- **Grief over physical and emotional losses-** The combination of significant losses and disrupted social development contributes to the sense of social isolation and loneliness that survivors may experience. Survivors describe the feeling that there are few people who can understand and appreciate their cancer experience.

- **Fear of losing loved ones-** Childhood cancer survivors have coped with a life-threatening illness and treatment. They deal with the fear of dying and losing their loved ones, and losing other children and friends they get to know while undergoing treatment.

- **Sense of meaning-** The experience of dealing with your own mortality at such a young age can enhance or awaken a sense of spirituality in children as they come to understand the preciousness and fragility of life. The meaning of life for these children and their loved ones is often realized with the diagnosis and treatment of cancer. These thoughts and emotions can cause comfort, doubt, anger, sadness and guilt.

Working with a professional trained to address these needs can be critical for the survivor and their loved ones over the course of their lifetime.

- **Survivor guilt-** For many childhood cancer survivors, the experience of a cancer illness and treatment occurs in conjunction with treatment of their peers' cancer as well. Children treated for cancer are typically clustered under the same outpatient and inpatient phases of treatment. Their medical providers are typically specialized and located at medical centers that address children's health care needs. This means children with cancer are usually treated in the same environment and get to know other children and families experiencing a similar diagnosis. Children with cancer may go to camp, clinic, support groups and hospital schooling with other children experiencing cancer and other life-threatening illnesses.

The experience of getting to know other children with a life-threatening illness meets some very natural needs those children have for socialization and normalization, even in a medical environment. However, the reality that some of these children die is also a common and realistic experience for these children while in and out of treatment. As these children survive and live past their initial or recurrent treatment experience, they may still stay in contact with other survivors who lose their battle with their illness. Survivor guilt is a common psychological reaction of childhood cancer survivors. Support and reassurance from loved ones can help children cope with the sometimes-repeated loss of friends.

- **Concerns of parents-** Parents often feel torn on many fronts — between protecting their child from the discomfort of the treatment and side effects, and doing everything possible to ensure his/her cure; between being constantly present for their sick child and caring for their well children at home; between maintaining a strong marital relationship and spending so much time separately in order to simply accomplish all that needs to be done; between maintaining limit-setting with the sick child and giving him/her almost anything wanted in the face of difficult treatment and possible death. Such juggling requires a redistribution of the roles in the family, which may be temporary or may continue long enough to become a habit long after the illness is over.

Once the survivor ends treatment, the family must find a new equilibrium which involves the sick child losing some of that extra special attention, parents re-instating realistic limits and expectations, and siblings feeling permission to live their own lives again. For the parents, relationships with family and friends may need to be adjusted from one of helpfulness, as treatment has ended, to relationships centered on helping the family adapt to having their lives return to some level of normalcy.

SPECIAL CONSIDERATIONS

Health Insurance

It is imperative that childhood cancer survivors not have a lapse in insurance coverage. Insurance coverage is important, because survivors need to have yearly medical follow-up that often includes laboratory and/or radiological studies depending on the type of cancer and specific treatment they received. Survivors should receive a comprehensive treatment summary when they are discharged from their pediatric oncologists. If a summary is not received, the survivor or family should ask that a summary be completed and a copy provided to the survivor for continuity in medical care. The summary should outline the care and follow-up needs the survivor needs to receive.

Laws governing health insurance vary in each state. Transitions between home and school, and school and work are periods of potential lapses in insurance. Understanding state insurance laws regarding insuring a minor and preparing for these transitions will help prevent lapses in health insurance.

If a young adult is not in school and his or her job does not provide benefits, she or he should explore coverage through organizations such as alumni associations, labor unions, professional and business organizations, student health, religious institutions and other special interest groups.

Importance of Healthy Lifestyles

With the risk of long-term side effects, it is especially important that survivors learn to promote positive health through a healthy diet and regular physical activity. Learning how to live a healthy lifestyle at an early age may set the stage for a healthier lifestyle as an adult. And despite being at an increased risk for certain future health problems, the cancer survivor can lower the risk for some of these problems by maintaining a healthy weight through diet and exercise and practicing healthy behaviors, including regular medical follow-up as recommended based

on their diagnosis and treatment. Healthy behaviors such as avoiding excessive sun exposure and use of tobacco are even more important for these children.

Sexuality, Fertility and Reproduction

Health care professionals are obligated to discuss the impact of chemotherapy, radiation therapy, and cancer related surgeries on a patient's fertility as part of an informed consent process. This process focuses on both the child diagnosed with cancer and the parents or legal guardians. The availability of sperm banking for families that can afford it and, to a lesser extent, the less widely available and far more expensive ovum banking, address fertility issues directly with the child with cancer but as an issue separate and apart from sexual functioning. Parents of well children struggle with notions that their child is a sexual person or even sexually active. Similarly for parents of children with cancer, notions of the child's sexuality are difficult and sensitive issues.

Young adult survivors of childhood cancer may therefore be confronted with changes in their fertility potential as well as changes in their body's appearance and ability to function sexually. If they have not participated in discussions with health care professionals about these highly intimate issues, they are left with doubts, concerns and worries that often go unaddressed. This further complicates re-entry in terms of interpersonal relationships, dating, sex and marriage. Helping a young adult survivor with sexual issues requires the assistance of a health care professional to review the survivor's treatment history as it relates to sexual functioning. Comprehensive medical follow-up for young adult survivors often needs to include an endocrinologist to address alterations and/or the impact of interruptions in hormone production. In addition some survivors can benefit from working closely with urologists or gynecologists who specialize in sexual dysfunction. On occasion, the young adult survivor can benefit from a consultation with a mental health professional who specializes in helping people with sexual concerns related to their medical treatment.



Psychosocially, the challenge is focused on meeting partners and establishing adult sexual relationships. Concerns about body image, disclosure of medical/ fertility issues and, at times, a general sense of feeling left behind by peers render the dating process particularly challenging. Role-playing and mental rehearsal are two of the crucial psychosocial interventions that can help young adult survivors begin to develop social ease in dating situations.

ROLE OF THE SOCIAL WORKER

Social workers across many practice settings may encounter a childhood cancer survivor or a loved one of a child with cancer as a client. The concrete strategies and information that social workers can provide to these individuals can assist the childhood cancer survivor to manage their long-term effects of survivorship. Some of these strategies are known to survivors, but additional education, support, and advocacy from social workers may help survivors and their loved ones with adherence to medical and psychological recommendations and coping with the effects of cancer survivorship. With the knowledge presented here as an overview for social workers, the strategies and information that are threaded are throughout this article and highlighted below:

- Complete a comprehensive assessment of the childhood cancer survivor including physical, cognitive, psychological, social and other special concerns;
- Include a vocational skills and employment history in the assessment, including any barriers to successful employment or educational opportunities;
- Educate survivors and their loved ones on resources for support, counseling, financial assistance, insurance, employment, self-advocacy, advocacy and any other information related to survivor needs;
- Offer support and counseling as appropriate in your role;
- Provide referrals and resources to the client and, with consent, on the client's behalf as needed; and
- Encourage the survivor to –
 - Keep follow-up medical appointments and seek medical care when needed;
 - Keep a copy of all medical records (including a medical summary of diagnosis, treatment, and recommendations for follow up care) and along to relevant appointments (let the provider make a new copy and encourage the survivor to always keep their own copy);
 - Lead a healthy lifestyle that includes compliance with medical recommendations as much as possible.



NATIONAL RESOURCES

National Association of Social Workers (NASW)

www.socialworkers.org

NASW has developed a course for social workers called *Understanding Cancer: The Social Worker's Role*. The web course is free to social workers and offers 2.0 CEUs, and includes information on childhood cancer and survivorship. The course can be accessed at www.naswweb.com

Alliance for Childhood Cancer

www.childhoodcanceralliance.org

American Cancer Society (ACS)

www.cancer.org

American Psychosocial Society

www.apos-society.org

Children's Oncology Camping Association International

www.coca-intl.org

Association for Oncology Social Work (AOSW)

www.aosw.org

Association of Pediatric Oncology Social Workers (APOSW)

www.aposw.org

Cancer Legal Resource Center

www.wlcdr.org

CancerCare

www.cancercare.org

Candlelighter's Childhood Cancer Foundation

www.candlelighters.org

Children's Cause for Cancer Advocacy (CCCA)

www.childrenscause.org

Children's Brain Tumor Foundation (CBTF)

www.cbtf.org

CureSearch

www.curesearch.org

Fertile Hope

www.fertilehope.org

Lance Armstrong Foundation (LAF)

www.livestrong.org

National Cancer Institute (NCI)

www.cancer.gov

A publication entitled *Late Effects of Childhood Cancer Therapies* (PDQ,) can be accessed at www.cancer.gov/cancertopics/pdq/treatment/lateeffects/patient

National Children's Cancer Society (Beyond the Cure)

www.beyondthecure.org

National Coalition for Cancer Survivorship (NCCS)

www.canceradvocacy.org

The *NCCS Cancer Survival Toolbox* can be accessed free of charge at www.canceradvocacy.org/programs/toolbox.aspx

National Hospice and Palliative Care Association (NHPCO)

www.nhpco.org

Oncology Nursing Society (ONS)

www.ons.org

Patient Advocate Foundation (PAF)

www.patientadvocate.org

Teens Living with Cancer

www.teenslivingwithcancer.org

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