

A young man and woman are smiling and hugging. The man is wearing a black and white striped shirt, and the woman is wearing a black and white striped shirt. They are in front of a stylized green background featuring a bridge and a city skyline. The text 'LIFE AFTER CANCER' is written in blue, with a white arrow pointing left below it.

# LIFE AFTER CANCER

Adnan, age 15,  
13-year Leukemia (ALL)  
survivor, with his sister,  
Nadine

*You gain strength, courage, and confidence by each experience in which you really stop to look fear in the face.*

*You are able to say to yourself, "I have lived through this horror. I can take the next thing that comes along."*

ELEANOR ROOSEVELT

## Life after Cancer

**T**HE END OF TREATMENT SIGNALS A NEW BEGINNING for cancer survivors and their families. There is relief that treatment has ended and desire to return to a normal life.

Survivors start planning for the future – to return to school, start a new career, and rekindle old ties and relationships.

At the same time, questions regarding issues that previously were not a priority, now arise to the forefront. From chronic pain, to possible job discrimination, to fear of relapse, some survivors may feel a need to learn more about the possible late effects of their treatment and its related implications.

It is important for all survivors to become knowledgeable about possible hurdles (e.g. difficulty in obtaining life and health insurance) that may impact them as they move out of ‘the patient’ mode. Becoming familiar with their rights, and what they are legally entitled to, will help them better navigate the system and become strong ‘self advocates.’

Remember, being a cancer survivor doesn’t define who you are or what you are capable of, but rather brings with it a chance for growth.

Life after Cancer			
1	Education	6	Post-Traumatic Stress
2	College	7	Chronic Pain & Fatigue
3	Careers	8	Fear of Relapse
4	Insurance	9	Relationships
5	Fertility	10	Advocacy

## Education

ONE OF THE STRONGEST MESSAGES AN ONCOLOGY health team wants to convey to childhood cancer survivors and their families is maintaining a sense of “normalcy” in life. There is nothing more routine or more normal for a child/adolescent/or young adult than going to school. It is their “job”—it is what gives them structure, meaning in their life, and a connection to their peers and the world they live in.

As childhood cancer survivors re-enter the educational environment, they may face physical, psychological, and academic challenges that need to be addressed. We now understand that certain types of cancer treatment can cause cognitive late effects that can minimally to greatly impact self esteem and educational success.

### Cognitive Effects of Treatment

The brain can be affected by certain chemotherapy drugs, radiation therapy, and surgery. Survivors at highest risk for educational issues may have undergone one or more of the following treatments:

- Leukemia (ALL)
- Brain tumors
- Tumors of the head and neck
- Bone marrow/stem cell transplant

#### Other factors that increase risk include:

- Young age, which places children at higher risk because of the brain’s rapid development during the early years of life.
- Female gender
- Increasing time from treatment

#### Radiation Effects:

- Highest risk
  - Young age (particularly < 3 years)
  - Higher dose

■ Whole brain radiation:

- 1800 cGy: risk for mild learning disabilities
- 2400 cGy: risk for more severe learning disabilities

■ For those treated for brain tumors, specific disabilities may depend on which area of the brain received the highest dose

**Chemotherapy:**

■ Two-thirds of all leukemia patients treated with chemotherapy alone experience some degree of neurocognitive late effects

■ Methotrexate (including intrathecal), steroids, and high dose cytarabine are most frequently associated with problems

- These drugs may also increase the cognitive effects of radiation therapy

**Surgery**

■ Surgery to the brain may also contribute to cognitive effects.

- Disabilities depend on the part of the brain that was operated on and any complications that might have occurred after surgery

**Types of Cognitive Issues**

Just like every person reacts differently to treatment, there is a wide variability in cognitive late effects as well. Some survivors have no learning issues, some have mild problems, and others experience effects that change their life and require a great deal of intervention.

Survivors may have impairment in any area of neurological function, but the most common problems include the following:

- Short term memory loss
- Attention and concentration
- Visual perceptual skills
- Difficulty with word retrieval
- Poor processing speed
- Poor reading comprehension
- Poor organization and executive function
- Difficulty with multi-tasking

Worsening academic performance is related to a reduced rate of skill acquisition rather than a loss of previously learned information.

Math, reading, and spelling are the most frequently reported problem areas.

Neuropathy, usually seen after chemotherapy with drugs such as vincristine, may cause difficulty walking and writing. Taking notes can therefore be painful.

For children with brain tumors, walking, seeing, hearing, and speaking are life functions that can become impaired due to the seriousness of the disease and side effects of radiation and surgery.

Careless errors, incomplete assignments, and inconsistent academic performance are common problems, and students often need extra time to complete their school work and take tests.

School difficulties may not necessarily manifest during the primary grades when learning memorization by rote is intact. Instead, they may become evident as survivors transition into middle school and high school, where organizational reasoning and time management skills become essential to successful school performance.

### **Educational Testing**

Extensive assessment through neuropsychological testing is often needed for childhood cancer survivors who are experiencing learning difficulties.

Neuropsychological testing involves giving a student a number of tests that provide information about how his/her brain works in the following areas:

*“There is a general lack of knowledge about late effects and learning problems. It took a long time and a lot of work to get my son the services and accommodations he needed at school. I had to keep pushing and bucking against the system. You are your child’s best advocate. Never give up in getting them what is needed.”*

—SUE, MOTHER OF A BRAIN TUMOR SURVIVOR

- Memory
- Speed
- Language
- Visual processing
- Auditory processing
- Integration of information
- Emotional and behavioral regulation
- Planning and organization

The tests are given by a trained professional (either a licensed psychologist or someone supervised by the psychologist). The purpose is to provide a comprehensive, detailed assessment of a person’s ability to encode, process, store, and express information. Interpretation of the various test results shows strengths and weaknesses that should then be shared with the school. From this evaluation, recommendations can be made for accommodations to assist learning and functioning.

Unfortunately, many health insurance providers do not cover educational testing. While school systems do provide their own testing, it is often not detailed enough. As a result, certain cognitive late effects unique to this population are often missed. The late effects team can assist parents by educating school personnel about the varied and specific academic challenges faced by survivors.

## Partnering with the School

When teachers see a student who has hair and looks well, they often forget their medical history, and what they have been through. There is a serious lack of knowledge of childhood cancer cognitive late effects amongst educators.

A critical component for successful intervention and outcome is a strong partnership between the medical team, the school team, parents, and the student. When this partnership is strong and cohesive:

- Educational needs of the student can be identified
- Accommodations can be determined
- Frequent communication amongst all involved parties can ensure success for the student

## What are Your Rights?

Some childhood cancer survivors require specialized education or specific accommodations to meet their needs. Learning differences that are not addressed, or handled in an insensitive or uninformed manner, can negatively impact a student's confidence, esteem, and educational achievement.

There are laws that provide childhood cancer survivors with the necessary educational services. They protect the rights of childhood cancer survivors who may be left with learning disabilities, attention disorders, medical problems, an amputation, or other physical limitations that prevent use of the full range of educational services.

These laws are based on the premise that education is a right, guaranteed to every citizen, regardless of physical, mental, or health impairments.

These laws apply to:

- infant, toddler, and pre-school programs
- elementary, middle, and high schools
- vocational education
- colleges/universities

### **Federal Individuals with Disabilities Education Act (IDEA)**

- Governs how states and public agencies provide early intervention, special education, and related services to children with disabilities
- Addresses the educational needs of children with disabilities from birth to the age of 21
- States that students must be provided a free, appropriate public education that prepares them for further education, employment, and independent living
- Requires that public schools create an Individualized Education Program (IEP) for each student who is found to be eligible under both the federal and state eligibility/disability standards

### **Individual Education Plan (IEP)**

Designed to meet the unique specific educational needs of one student

Tailored to the individual student's needs as identified by the evaluation process

Describes the student's present levels of performance and how the student learns

Describes how the student's disabilities affect academic performance

Specifies accommodations and modifications that teachers need to make to help the student learn more effectively

- The IEP must include the following:
  - Description of the student’s present level of educational performance
  - Measurable annual goals, objectives, and benchmarks
  - Special education services, related services, and supplementary aids to be provided to the student
  - Setting in which each designated goal and objective will be met
  - Schedule of services to be provided, including when the services are to begin, and the frequency, duration and location for the provision of services
  - Program modifications or supports provided to school personnel on behalf of the student
  - Explanation of any time the student will not participate along with non-disabled children
  - Accommodations to be provided during state and district assessments that are necessary to measuring the child’s academic and functional performance
  - Evaluation of the IEP needs reviewing at least once a year to ensure goals are being met, evaluate progress, and address any concerns

#### **The Federal Rehabilitation Act “504 Plan”**

- A law known as the Section 504 of the Rehabilitation Act of 1973 offers students with disabilities or health care needs the services and accommodations that are necessary for the student to participate fully in school
- A 504 plan is used by a general education student who is not eligible for special education services or an IEP
- To receive services under section 504, a student must have a mental or physical impairment that substantially impairs one or more major life activities and requires special accommodation

- The 504 lists accommodations related to the student's disability that are required by the student so that he or she may participate in the general classroom setting and educational programs

### Examples of 504 Plans

Plans for additional time to travel between classes or use of an elevator due to difficulty walking or climbing steps

Permission to type assignments instead of writing by hand

Permission to use a computer in class rather than take notes

Extension on timed tests

### The process for developing a 504 plan needs to include:

A school evaluation

A letter from the student's doctor or neuropsychologist describing the disability, related problems, and needed medications and/or treatments

Written plan identifying the accommodations to be provided, both physical and instructional

Periodic review of services

## College

**C**HOOSING A COLLEGE AND THEN A CAREER IS A very exciting time in any survivor's life. It is the beginning of more independence and responsibility. It is also a time to explore new ideas, make new friends, and discover new things about yourself.

Many young adults graduating from high school feel both excitement and anxiety as there are many decisions to make:

- Do I want to go to college?
- Do I feel ready to go to college?
- Do I want to get a job and take evening classes, or just take some time off from school for a while?
- What are my interests? Do I know what major to choose?
- Are my interests and skills a better match for a vocational school?
- Do I want to live away at school or commute from home?
- If I do live away, how far from home do I want the school to be?  
Do I want to go out of state?
- Is my personality a better fit for a large university or a smaller, more close-knit college?
- What can my family afford? Am I eligible for financial aid, scholarships and student loans?

All these questions and concerns are perfectly normal.

Cancer survivors may face other considerations as well. For example, some young adults feel nervous about being far from home and familiar doctors. This is especially true if you are at the end of your treatment or just finishing with it and need frequent follow-up. Others see this as a time for a completely new beginning and want to go farther away. Remember, there are no right or wrong answers—choose whatever feels comfortable for you.

*“I finished treatment at the end of my junior year. The whole college decision was just too much. I needed time to get my life back and clear my head. I am working at a national park near where I live and taking classes at the community college. I still don’t know what I want to be when ‘I grow up.’ Right now I am just enjoying getting to that point.”*

CARLOS, 18 YRS. OLD, GERM CELL TUMOR SURVIVOR

Survivors also worry about being accepted into school or being denied admission because of their history of cancer.

### **What are Your Rights?**

It is against the law to deny admission to a student with a disability. Your rights are protected by both state and federal law.

The **Americans with Disability Act (ADA)** protects you against any educational discrimination and prevents schools from turning away students based on their medical history or disability as long as they meet the academic requirements for admission.

The **Federal Rehabilitation Act (FRA)** ensures that any public or private school that receives funds from the government is banned from discriminating against any student on the basis of a disability.

Both these laws are discussed in more detail later in this section under ‘Careers.’

*“I found college to be a wonderful experience, and having had cancer made me appreciate and treasure it all the more. My years in college were a time for learning about the world around me and myself. I made many important relationships and learned a lot about myself.”*

RANDY, 28 YRS. OLD, BRAIN TUMOR SURVIVOR

## **Making Decisions**

When you are making a decision about what college to attend, consider any special learning or physical needs you may have. Ask yourself and the college very specific questions such as:

- Will this school provide extra services that will help you such as untimed tests, tutors or notetakers?
- Can you get around campus easily or will you need transportation from class to class?
- Is there someone to help you if carrying books is too hard?
- Can you take fewer classes in a semester?
- Is the college atmosphere a good fit for you?
- Are summer courses an option?

## **Useful Tips**

- Use as many resources as you can to gather information and ask questions such as the library, the internet, and your guidance counselor
- Talk to other students who attend the schools you are interested in
- Visit the campus, especially while classes are in session, so you can get a real sense of the school

- Some colleges require interviews as part of the application process. Use this as an opportunity to ask questions and to interview THEM to learn if this is the environment that will give you the college experience YOU want
- Look for scholarship opportunities specific for childhood cancer survivors. (several are listed in the Resources section)

This is a wonderful time in your life. Take advantage of every opportunity that comes your way and run with it, grow with it, and have a great time!

## Careers

**M**OST SURVIVORS COMPLETE HIGH SCHOOL AND go on to college and graduate school to pursue their desired careers. They are accountants, teachers, mechanics, nurses, computer experts, doctors, dancers, lawyers, actors, and secretaries—just like everyone else. Work is an important part of one's life, so making a career out of something you enjoy doing and are good at can contribute significantly to your overall happiness and sense of purpose.

Work also fills other important needs such as finances and insurance. While a survivor's rights are protected better than ever today, a history of cancer can still create barriers to finding or changing jobs.

### What are your Rights?

#### **Americans with Disabilities Act (ADA)**

- This act protects employees against job discrimination based on disability, a history of disability, or a perceived disability by employers, employment agencies, local and state governments, and labor unions
- The ADA states that no employer may ask an applicant any medical questions unless the employee has an obvious disability (i.e., eye patch, hearing aid, amputation), or the employee talks of his disability of his own choosing
- Any questions asked, may only be directed at how the applicant will be able to perform the job itself
- Employers ARE allowed to ask medical questions after they have made a job offer or during the employment medical exam
- Employers are also not allowed to discriminate because of family illness (i.e., if your child or wife has cancer, you cannot be treated differently because this will make the insurance costs higher to the company or because you may miss work)

*“May 15<sup>th</sup>, 2006 was the best day of my life, as I put on my cap and gown and walked to the sound of ‘Pomp and Circumstance’ playing at my medical school graduation. My thoughts went back to 1998 to the day I received the diagnosis of Stage IV Hodgkin Lymphoma. I am here to tell you—NEVER give up on your dreams! It may take a long time to get where you want to go, but that’s okay. If you can beat cancer, you can achieve anything you want in your life.”*

ANTOINE, 27 YRS. OLD, HODGKIN'S LYMPHOMA

- An employer does not have to provide health insurance as a benefit, but if they do offer it, they must provide it fairly to all employees

If for any reason you feel you have been discriminated against based on your history of cancer, you can contact the Equal Employment Opportunities Commission (EEOC) (<http://www.eeoc.gov>).

For those survivors living in Canada, the Canadian Human Rights Act covers the same rights as the ADA.

### **The Federal Rehabilitation Act (FRA)**

- The FRA protects employees that work for the following organizations against discrimination:
  - the federal government
  - organizations/employers that receive federal contracts
  - organizations/employers that receive federal financial assistance

*“I seemed to take some bumpy roads before settling in on my career. I started college away from home, but it just wasn’t the right fit. I then returned home, completed my associated degree at a community college, and then transferred to another university to complete my degree. By then I knew that I wanted my career to involve my childhood cancer experience. This fall, I was 1 of 20 students selected into a Masters program for Art Therapy. After graduation, I hope to work with children with cancer. I want to make a difference for them and share all the important lessons I learned on this cancer survivorship journey.”*

LESLIE, 24 YRS. OLD, EWING’S SARCOMA SURVIVOR

### **Family and Medical Leave Act (FMLA)**

The FMLA provides job security for those employees (working for large companies) who must take a leave of absence from work to care for a sick child or close family member, because of their own illness or because of the birth, adoption, or foster care of a child.

- The employee is given twelve weeks without pay, but continues to have benefits and health insurance
- The employee will still have the same or equal job when he/she is able to return to work
- In order to be eligible for this, an employee must have worked at least 25 hours/week for one year

## Other Job-Related Issues

Although there are laws to protect you against discrimination, there are some general guidelines you should consider when looking for a job.

- Have your resume prepared by a professional and practice interviewing skills
- Review all job descriptions to make sure you are qualified.
- As a general rule, the larger the company, the fewer the issues related to health and life insurance
- Know and understand your rights and remember that you cannot be turned down for a job that you are qualified for, just because you are a cancer survivor

## Suggestions for Job Interviews

- Do not volunteer information about your cancer history
- Employers only have the right to see if you can do the job
- Employers do not have the right to ask for any personal or confidential information during an interview
- Under the Americans with Disabilities Act, employers can't ask about medical history, require you take a medical exam, or ask for medical records unless they make you a job offer
- Do NOT provide false information during a job interview. You can be fired later if your dishonesty is uncovered. Answer ONLY the specific questions asked
- Do not ask about health insurance until you have been offered the job. Before accepting the offer, review all benefits information carefully
- If your medical history does become an issue, obtain a letter from your doctor that briefly outlines your history, but emphasizes your present good health and ability to do the job. Ask to see the letter before giving it to your potential employer. You may want to write the letter and have the doctor sign it

- Contact the Equal Employment Opportunity Commission or visit its website for more information (<http://www.eeoc.gov>)

Abstracted with permission from the National Coalition for Cancer Survivorship's, A Cancer Survivor's Almanac, [www.canceradvocacy.org](http://www.canceradvocacy.org).

### **Military Service**

- Survivors of childhood cancer are usually not allowed into the military
- There are some exceptions, but they are considered on a case-by-case basis
- To see if you are eligible, contact your local military recruitment office

## Insurance

**U**NFORTUNATELY, CANCER SURVIVORS MAY FACE discrimination when trying to obtain health and/or life insurance. Some are denied, restricted, or pay more premiums because of their medical history. Making sure you have the insurance you need takes time to research. You need to be knowledgeable as well as persistent. Contact your state insurance commissioner with any questions or to file a complaint.

### Health insurance

While it is very important for survivors to have health insurance, it may be difficult to obtain. Survivors have faced problems because of their past medical history. Policies have been cancelled, coverage has been reduced, premiums have increased, or waiting periods have been extended. Healthcare in general is a much debated topic in the United States and reform is needed in many areas. Until the laws become fairer and in your favor, you need to be your own strongest advocate.

There are different types of policies: group, individual, and government plans.

#### Group plans

- These are usually obtained through your place of employment (or your partner's)
- The larger the number of employees, the less likely it is you will be rejected from coverage
- Depending on the policy, you may not even need to answer any health-related questions
- Organizations such as labor unions, professional or business groups, and special interest groups may also have group policies. Find out if you are eligible

### **Individual plans**

- If you cannot get a policy through a group, consider the available individual plans, though these are usually much more expensive
- You may want to ask about other options such as:
  - Extending your policy on your parents' plan (a cancer history may qualify you as "disabled")
  - Finding out if your state has a catastrophic insurance pool and if you are eligible for participation
  - Getting coverage through your partner

### **Government plans**

If you cannot get medical coverage through a group or individual plan, evaluate the government programs:

#### ■ **Medicaid**

- An insurance plan for non-senior citizens with limited incomes
- Contact your area social service department to locate the Medicaid office in your area
- Medicaid usually covers doctor and hospital bills, medicine, physical/occupational/speech therapy and home health aides
- Each state has its own requirements and coverage

#### ■ **Medicare**

- A federal plan for seniors and disabled persons with very specific criteria
- Contact your local office to see if you are eligible

#### ■ **CHIPS**

- High risk insurance pools for individuals regardless of their physical condition or medical history
- Information on this plan can be obtained from your state insurance commissioner

## What are your rights?

### COBRA

- According to federal law, all companies, both public and private, that employ more than 20 employees must provide continued health insurance for 18 months to all workers if they quit, are laid off, or reduce their hours
- The coverage must include all family members
- The employee must pay the premiums, but at the rate (plus no more than 2%) that the current employees in the company are paying
- COBRA allows time to seek other health coverage

### ERISA

- A federal law that protects workers from being fired because of their cancer history or that of their beneficiaries (partner and children)
- It also prohibits employers from encouraging someone to retire as a 'disabled employee' because of their history of cancer
- ERISA does not apply to job discrimination or discrimination that does not affect benefits

### Kennedy - Kassebaum Law

- If a person has been employed for 12 months, this law allows them to change jobs without losing coverage
- It also prevents group health plans from denying coverage based on medical history, genetic information, or claims history

## Life insurance

Life insurance is essential for replacement of wages if the primary family wage earner dies. It may seem unnecessary to even think about this if you are not married or have no children. However, life insurance is generally less expensive when you are younger. If you are even thinking of marriage and children, it is a good idea to get it.

When a low-cost opportunity comes your way, consider buying the maximum amount you can afford.

- Many insurance companies have strict requirements that exclude individuals with a previous serious medical illness. This includes survivors, even those who have been cured for a long time
- Usually large corporations and government agencies offer life insurance as a benefit. These plans usually don't evaluate each person in the plan or their partner and children. They usually have good coverage at affordable rates and there is sometimes no waiting period
- The easiest time to either purchase more insurance or put yourself in a plan is during open enrollment at your place of employment. Most companies have at least one time during the year that you can sign up and not have to give a medical history
- You can buy life insurance through private companies, but you usually need to buy it through an insurance agent

To find out what information insurance companies have on your medical history, contact the Medical Information Bureau (MIB) ([www.mib.com](http://www.mib.com)), the largest private health information bank.

Tell the truth on your forms when applying for any type of insurance. Sometimes questions will be asked such as, "Have you been treated for cancer within the last five years?" If you have been off treatment longer than this, you can truthfully answer no. If an insurance company ever learns that you lied about your past medical history, you could lose your benefits.

*“I was looking at myself in the mirror, crying after receiving a denial for payment from the insurance company stating I was too young for a procedure I had undergone a few days ago. I had just been diagnosed with a rare form of breast cancer at the age of 29 as a result of long term effects of my previous cancer treatments. Payment was being denied for the very tests that had helped make my diagnosis (mammogram, biopsy etc).*

*I wanted to call the insurance company; rant and rave that this was not like going to the DMV at 16 for a driver’s license; this was my health and life they were denying. Instead I piled all my insurance claims together, wrote a letter to my insurance company and became my own self advocate.*

*I went to doctors and had them write letters while I was undergoing chemotherapy and lumpectomies. A few weeks later I received a letter in the mail from the insurance company apologizing and informing me that everything would be re-submitted and paid for. That day, I thought to myself, ‘I wonder how many other survivors and parents go through this everyday, fighting the system for tests and treatment they need to take care of late effects related issues’. The best thing a parent or survivor can do is educate yourself about your past history and stand up for your self as your own advocate.”*

KELLY, 29 YRS. OLD  
ALL, MELANOMA, THYROID AND BREAST CANCER SURVIVOR

## Fertility

**W**HEN A CHILD OR ADOLESCENT IS DIAGNOSED with cancer, the discussion of cancer therapy is difficult and complicated as the oncologist describes the treatment, side effects and potential late effects related to treatment. During this very stressful time, when parents face the potential reality of losing a child, much of the information regarding the potential for infertility is often not remembered or understood.

Later, as treatment comes to an end, and the time interval from completion of therapy lengthens, questions regarding fertility and gonadal function begin to surface.

One of the biggest concerns survivors express at this time relates to their ability to have children after they have received treatment. The loss of fertility or the fear of impaired fertility can affect the developing body image, dating relationships, and marriage patterns of survivors.

The loss of not being able to have one's own child can be absolutely devastating.

Many people dream about having children as an extension of their love for their partner. For them it is a hard dream to let go of, especially as a result of a disease that already was so difficult. For many survivors, this reality can take some time to process and accept.

There are certain factors that influence a survivor's ability to have children. Generally, those most likely to experience infertility or difficulty with fertility are:

- Survivors who received high doses of alkylating agents, high doses of radiation, or total body irradiation
- Males with direct radiation to the testes
- Females with direct radiation to the ovaries

All survivors treated before puberty, as well as all females, seem to be less affected by treatment than survivors treated after puberty and males.

It is important to remember that every survivor is unique and that everyone's body reacts differently to treatment. There are survivors who have been told they would never have children and have either become pregnant or fathered children.

Modern medicine is constantly changing and new treatments and techniques such as sperm banks, ovarian cryopreservation, and in vitro fertilization are continually being developed to help infertile couples have children.

In making the decision to have children, you need to ask yourself some serious questions and consider the following issues:

- Am I ready to have children?
- Do both my partner and I want children?
- Am I in good physical health to get pregnant and to carry a child?
- Have I sought expert advice on the risks involved, especially those related to the specific treatment I received?
- Is my obstetrician (doctor for pregnant women) a high-risk specialist—meaning is he/she capable of managing any risk I may have related to my treatment?
- Have my partner and I considered what infertility methods we might try? Some of these include:
  - In vitro fertilization
  - Donor eggs
  - Donor sperm
  - Surrogate mothers
- Have the risks to each of these fertility methods been explained to us, and are we willing to take those risks?
- Did I have the type of cancer that is genetic and could be passed on to my child?
- Have we considered genetic counseling?

- If we are able to have children, will they be healthy?
- Will we consider adoption?

It is also important that should you not want any children, you and your partner use birth control. Never assume that the treatment you received is a substitute for contraception.

### Health of children

Survivors may also be concerned about the health of their future children as a result of the treatment they received. Can the chemotherapy, radiation therapy, or surgery they received cause birth defects or disabilities? Can they pass their cancer on to their children?

In general, children of childhood cancer survivors appear to be as healthy as babies born to people who never had cancer.

There are some survivors who need to be counseled regarding certain risk factors. They include:

- Survivors of retinoblastoma (often a hereditary cancer) have the possibility of passing this same gene to their children, thus making it likely that they will have retinoblastoma as well
- Female survivors who received radiation therapy to their pelvic area may have a uterus that does not expand as well. This could lead to premature labor or a low birth-weight infant
- Survivors with a family history of cancer

*"I am a four time cancer survivor, have a wonderful husband and two small healthy children. I was diagnosed with leukemia a month before my fourth birthday and had 3 CNS relapses, chemotherapy, radiation, and numerous surgeries. My parents and I were told that I had a 3% chance of having children in the future because my female organs had been damaged to the extent of not being able to reproduce. I married my wonderful husband, Josh, in September 2002, and in late January 2003, I started having flu like symptoms. In February, after 14 positive home pregnancy tests, my husband and I realized it was not the flu, "WE WERE PREGNANT!!" How could this be? Doctors had said for years that pregnancy was impossible. On September 16, 2003, we had a healthy baby boy, Jake, and in December 2005, we were blessed with a baby girl, Emelia Rose.*

*If I could give any inspirational advice, it would be never give up, especially when it comes to faith, hope, and love. God blessed me with 2 beautiful children that I thank Him for every day, and I thank him for letting me be a survivor because that alone, is a blessing in itself."*

KELLY, 29 YRS. OLD  
ALL, MELANOMA, THYROID AND BREAST CANCER SURVIVOR

## Post-Traumatic Stress Disorder

**W**HILE MANY SURVIVORS WILL SAY THAT CANCER changed their life in a positive way and gave them great insight, the harsh reality of a cancer diagnosis cannot be overlooked. Just as it is important to recognize the beneficial outcomes, it is equally important to acknowledge the difficult and painful aspects as well.

Post-traumatic stress disorder (PTSD) is a continuing emotional reaction to a past traumatic event in your life.

It is not at all unusual for survivors of childhood cancer to experience PTSD. While research in this area is not abundant, health care providers are beginning to study the long-term impact of a diagnosis of childhood cancer. Young adults, more than children and adolescents, are consistently impacted by the enormity of the cancer treatment they received and its long-range implications.

Symptoms of PTSD can occur when survivors enter the hospital for routine check-ups and encounter smells, sights, and sounds that trigger memories of their experience with cancer.

Specialized treatments to address PTSD are available through a range of mental health providers, including art therapists. Some licensed counselors and therapists employ EMDR, a desensitization technique designed to reduce anxiety and promote integration of traumatic experiences.

### Tips on Enhancing Quality of Life

▶ Regular exercise

▶ Pilates

▶ A healthy diet

▶ Hobbies

▶ Yoga

▶ Journaling

▶ Meditation

▶ Listening to music

*“Expect trouble as an inevitable part of life and when it comes. Hold your head high, look it squarely in the eye and say, ‘I will be bigger than you. You cannot defeat me.’*

—ANN LANDERS

### **According to some young adult survivors:**

- They have experienced anxiety about their lives being in danger
- They feel the fragility of their own life is more imminent as they become involved in intimate relationships, marry, and have their own children
- They worry about health risks such as possible cardiac damage, infertility, and secondary cancers from previous treatment

It is very important for childhood cancer survivors to understand that their feelings are completely normal given the challenges they were forced to face by their illness.

If you are a childhood cancer survivor experiencing symptoms of PTSD, there is nothing to be ashamed of. You are not alone. The most important steps you can take are to recognize that there is a problem, seek professional counseling, and surround yourself with positive support from family, friends, and other survivors.

## Chronic Pain and Fatigue

**L**IVING WITH CHRONIC OR PERSISTENT PAIN AND/OR chronic fatigue can be overwhelming, depressing, and affect quality of life. Unfortunately, many childhood cancer survivors experience some level of ongoing pain or fatigue after their treatment has ended.

The causes of chronic pain vary, and can result from complications of cancer treatment:

- Post surgical complications (e.g. scar tissue, adhesions, arthritis)
- Effects from radiation therapy
- Effects from chemotherapy
  - Permanent peripheral neuropathy due to nerve injury that causes burning, numbness, or weakness in hands and feet
  - Bone pain or osteoporosis from steroid treatment

You should not have to live your life in pain! There are many ways to effectively treat pain so that you are able to do the things in life you enjoy and that are important to you. The most important thing is to communicate with your health team about your pain even if they don't ask about it.

### Treatment Options for Pain Management

There are different treatment options for pain which can be used alone or in combination with each other.

#### Medication Options

- Mild pain: painkillers such as acetaminophen (Tylenol) or nonsteroidal anti-inflammatory drugs (NSAIDS) are effective
- Moderate pain: medications that combine an opioid (sometimes called a narcotic), such as hydrocodone or oxycodone, with acetaminophen or aspirin may be needed. Vicodin and Percocet are examples of these combination drugs

*“I have lived with chronic pain for ten years now and it’s still not holding me back from achieving my dreams. I have always wanted to work in the film business and after I graduated college I had an opportunity to do so. Never did pain hold me back from thriving in the business. Since then I have worked exclusively with “A-Lister’s” such as Ridley Scott and Tom Hanks to name a few. Don’t let pain stop you from living your dreams.”*

GREG, 25 YRS. OLD, OSTEOSARCOMA SURVIVOR

- Severe pain: stronger medications that contain an opioid only (sometimes called a narcotic) such as long-acting morphine, oxycodone, fentanyl or methadone are usually needed
- Adjuvant medications: may be used for the management of neuropathic pain. These are medications with primary uses for other conditions, but which are effective for certain kinds of pain. Examples include the antidepressants Elavil and Cymbalta
- If medication does not effectively control your pain, a technique called ‘nerve block’, where medication is injected into the spinal column to block the nerves, may be used

#### **Non-Medication Treatment Options**

Non-medication treatment options: are effective for both, chronic pain and chronic fatigue:

- Acupuncture
- Massage
- Biofeedback
- Relaxation and Imagery
- Hypnosis

## Tips to Manage Chronic Pain

### Keep a record of your pain

- ▶ Include words that describe your pain
- ▶ Rate your pain on a 0-10 pain scale
- ▶ List activities that seems to increase or decrease the pain
- ▶ List activities that you cannot do because of the pain
- ▶ Record name, dose, and time of any pain medicine taken and how effective it is in eliminating or reducing the pain
- ▶ Record how long any medicine you take is effective
- ▶ List any side effects you have from the medication

### Develop a plan to treat your pain

Forming a strong partnership with your health care team is essential for good pain management

#### Be consistent with communication and follow-up

Always report if a new pain occurs or if the pain changes or worsens

### Remember

- Talking about pain or fatigue or being treated for pain is not a sign of weakness
- Taking medication to treat your pain is also not a sign of weakness.
- Not everyone feels pain the same way and no one can judge another person's pain
- It is important to address any of these feelings with your health care team

## Fear of Relapse

**T**HE LIVES OF CHILDHOOD CANCER SURVIVORS and their families are never the same once they have gone through the cancer experience. As patients complete their treatment, they are relieved that they are in remission, yet thoughts of the possibility of relapse are never far from their minds. However, survivors are all unique and each one deals with these thoughts differently.

Most survivors occupy themselves in regaining 'normalcy' in their lives through return to school, job, or a career. They try not to think about relapse on a daily, weekly, or monthly basis. Others are reminded of it each time they have to go in for a check-up or scans. Some spend their lives thinking of relapse almost every day; they may, even years later, continue to have unprovoked nightmares and anxiety attacks.

Anniversaries of the day of diagnosis are usually a difficult and emotional time for most cancer survivors and families. Many get anxious as they relive those scary first few days following diagnosis and worry about the disease coming back. On the other hand, anniversaries of the last day of treatment are times for celebration. As time passes, the fear of relapse decreases, especially in survivors who have few to no late effects of treatment. Gradually, anniversaries get forgotten and memories get filed away.

It is normal to have thoughts of the possibility of relapse in the back of your mind. However, if these fears continue over an extended period of time and interfere on a regular basis in your daily life, it is important to obtain mental health support. Individual or family counseling and support groups may help dispel the fears and provide suggestions for dealing with them in a constructive manner.

*“I don’t like to think about my cancer. It seems so far away. ‘I have moved on, out of the cancer world’. I don’t want to do anything with cancer survivors or their programs. My mother is still involved in the parent group at the hospital. Every now and then, she mentions a patient who is not doing well. It makes me think of the possibility of relapse. I don’t like to think of relapse. If the disease comes back, I will deal with it then. Not now!”*

PETER, 24 YRS. OLD, LEUKEMIA SURVIVOR

## Relationships

**T**HE END OF TREATMENT SIGNALS CHANGES IN relationships for the survivor with parents, siblings, caregivers, and friends. Old relationships change their nature, while new ones are established.

The most noticeable change that occurs is in the family dynamics. At the time of diagnosis, the entire social structure of the family undergoes a stressful re-organization. Roles and responsibilities change as parents try to balance their jobs, take care of the ill child, and attempt to spend time with the other children at home. The child or adolescent may become increasingly dependant on the parents, physically and emotionally, while the siblings may experience feelings of guilt, fear of abandonment, anger, jealousy, concern, and resentment towards the patient.

All this changes when treatment ends.

### Relationships with Parents

The survivor, especially if he/she is an adolescent, wants to resume his/her journey towards independence. Often, however, some parents may not be ready to let go. Both, the survivors and the parents, may have different ideas on what life after cancer should be like.

- Some adolescent and young adult survivors want to leave their cancer behind and get on with their lives. If the parents share this view, a smooth transition to adulthood occurs
- Some parents may want their child to move on and pretend the cancer never happened. However, if the survivor is not ready, this may create conflict

In some cases, cancer results in disabilities that affect the survivor's ability to live independently. Some may never be able to live on their own, while others return home intermittently for health or financial reasons. This creates a tremendous challenge for the entire family.

- Parents have to adapt to having an adult child in the house
- They also have to make arrangements for care when they are no longer able to provide it

Adult survivors sometimes re-visit their cancer experience by drawing on their parents' memories. This helps them gain an understanding of the trauma from their parents' perspective and allows for a closer relationship.

### Relationship with Siblings

The effect of cancer on siblings can be long-lasting. The diagnosis, treatment, and aftermath can all create conflicting feelings in the siblings.

- These can range from anger, resentment, and jealousy towards the survivor to compassion, sharing, and close relationships between them
- If these emotions become too difficult or painful, family therapy may be needed
- Many siblings benefit from the experience of having dealt with cancer through an increase in knowledge about health and disease, increased empathy for the sick, and greater maturity
- Many of the siblings choose professions related to medicine, teaching, or social work

### Relationships with Friends

The stability of friendships is usually directly related to age.

- When the diagnosis occurs in **elementary school**, friendships often depend on which classroom you are in and who sits next to you in class or for lunch. When the child returns after a long absence, friends may welcome him/her or the groups may have changed and moved on

*“One of the most difficult things I experienced besides my diagnosis of osteosarcoma, was losing my best friend to the same disease 2 years after we both completed treatment. I still remember the first day I met her. We were both new in our diagnosis and there was instant bonding between us. We were inseparable for the year of treatment and even planned our hospital admissions together. We went to camp together for 2 years and were known as the ‘twins’. Her disease came back suddenly and before I knew it, she was gone. I miss her so much and still carry this burden of guilt that I survived and she did not.”*

MEGHAN, 18 YRS OLD, OSTEOSARCOMA SURVIVOR

- In **middle school**, friendships often dissolve as tight knit social groups are forming. Peer pressure is high and compassion is difficult to find
- In **high school**, students begin to mature and some friendships may actually strengthen throughout the treatment

Friendships that form with other patients in treatment are usually very close. It is very difficult for survivors to lose friends with cancer and they often undergo survivor’s guilt.

## Advocacy

**A**S LIFE CONTINUES AFTER TREATMENT, MANY survivors feel a need to give back and contribute something to others. Survivors and their families have the potential to affect individual, institutional, and social change.

Advocacy means using this power so that you or other survivors can get what you need to live the healthiest life possible. Advocacy can be on an individual level or with a group.

### Individual advocacy

Individual advocacy means being able to stand up for yourself in order to get your own needs addressed for the rest of your life. This means learning to use the system so that you can get the best healthcare, an adequate education, and a job that will not discriminate based on your history of cancer.

### Group advocacy

Group advocacy means meeting with up with several survivors, and then large groups of survivors and their supporters, to help meet the needs of others and create change at the community, state, or national level. Issues that can be addressed include lobbying for more money for late effects research funding, improving insurance benefits for survivors, or opening more follow-up clinics.

Working with other survivors can have a powerful and positive effect on creating change. Together they can:

- Raise money for research
- Raise awareness among politicians about survivorship issues
- Improve insurance policies for survivors
- Attend large conferences of survivors to discuss issues
- Raise public awareness of what survivorship is about by talking about your own experiences

*“Once I was done with my treatment, I returned to law school and graduated 2 years later. I was hired by a prestigious firm and started making good money with great benefits. However, I knew I wanted to do something more for those who were still struggling without health insurance. I got together with a couple of other cancer survivors, and we started working ‘pro bono’ for children with catastrophic illnesses, especially cancer, who had no health insurance at diagnosis. It is one of the best decisions I made at the time. Today, I am part of a bigger organization that lobbies for political change at the national level.”*

FRED, 40 YRS. OLD, LYMPHOMA SURVIVOR

- Create networking groups for jobs
- Create support groups within your own area and through the internet
- Work with nurses, doctors, and teachers to raise their awareness of survivor needs
- Reach out to new survivors and offer help
- Reach out to families of children newly diagnosed with cancer
- Volunteer at a camp for children with cancer