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Overview



The **Pediatric Cancer Survivorship Learn Guide** is designed to help support patients and their families as they face the challenges of their cancer journey.

This guide is interactive and serves as a creatively driven resource developed to support, educate and empower both patients, and their caregivers.

Here are a few ways that this guide can be used as an ongoing resource:

- **After Treatment** includes video chapters 1-3 and features Dr. Leonard Sender, Dr. Lilibeth Torno, and Monica Lee, RD. This is the segment that you want to focus on while you're in treatment.
- **First 5 Years** includes video chapters 4-7 and features Dr. Lilibeth Torno and Monica Lee, RD. This is the segment that you want to focus on during post-treatment and the first 5 years of survivorship.
- **Journey to Wellbeing** and **Independence** includes video chapters 8-13 and features Dr. Leonard Sender and Jenee Areeckal, Pediatric Oncology Social Worker. This is the segment that you want to focus on while you're moving from pediatric to adolescent and adult care, and planning for long-term wellbeing.

We suggest that you bring your ebook of this guide to meetings with **Healthcare Professionals**. You can get the ebook from the "**Request this Ebook**" button above and will then be able to use it on your phone, tablet, computer, or print it out on paper.

Introducing Dr. Sender



Leonard Sender, M.D.

A nationally-recognized expert, **Dr. Sender** serves as the director of the Adolescent and Young Adult (AYA) Cancer Programs at CHOC Children's, leading one of the nation's largest programs focused on the unique needs of cancer patients ages 15-39 years old.

As a pioneer in oncology treatment for more than 20 years, Dr. Sender specializes in treating adolescents and young adults (AYAs), a largely unknown and underrepresented group in the war on cancer. His team offers a comprehensive approach toward AYA patient cancer care and survivorship that considers their unique challenges, including preservation of fertility, management of acute and chronic effects of treatment, and the psychosocial impact.

As an innovative leader in research, Dr. Sender is conducting extensive studies to improve outcomes and quality of life for AYAs. A passionate advocate for AYAs with cancer, Dr. Sender serves as chairman of the organization Stupid Cancer. He is a founding member and chairman of SeventyK.org.

"I'm Leonard Sender. I'm the medical director of the Hyundai Cancer Institute at CHOC Children's Hospital, and I've been involved with pediatric cancers, adolescents, and young adults for nearly 30 years. The thing I want to say to a patient who has just completed their treatment is, firstly, congratulations and, secondly, well done. What we need to talk about now is how we get you to your new normal, how we get you to adulthood, how we understand all the consequences of the therapy that you've been through, and how we make sure that you truly have wellness going forward."

To Learn More:

- Dr. Sender's Full Bio (<http://www.choc.org/providers/oncology/leonard-sender-md/>)
- The Hyundai Cancer Institute at CHOC Children's (<http://www.choc.org/cancer/>)
- Stupid Cancer (<http://stupidcancer.org/>)
- SeventyK (<http://www.seventyk.org/>)

Introducing Dr. Torno



Lilibeth Torno, M.D.

Dr. Lilibeth Torno is the Clinical Director, Outpatient Services and the CHOC ACTS (After the Cancer Treatment Survivorship Program). She also leads the Ambulatory Care Services of The CHOC Cancer Institute and directs the CHOC Long Term Follow-up Clinic for survivors of childhood cancer. The outpatient clinic provides comprehensive care of children undergoing chemotherapy, as well as those who have completed therapy. She is board certified in pediatrics and pediatric hematology/oncology. Dr. Torno completed her fellowship training at Children's Hospital of Los Angeles. She completed her residency at CHOC. She attended medical school at University of Santo Tomas, Manila, Philippines.

*"My name is **Lilibeth Torno**. I'm a cancer specialist, and I take care of childhood cancer survivors. I lead a program called After-Cancer Treatment Survivorship Program. I have worked at CHOC for approximately 15 years. The most important thing I would say to a child who just finished therapy is congratulations, this is a major achievement in your cancer journey."*

To Learn More:

- Dr. Torno's Full Bio (<http://www.choc.org/providers/oncology/lilibeth-torno-md/>)
- After Cancer Treatment Survivorship Program (<http://after%20cancer%20treatment%20survivorship%20program>)
- Cancer Resources for Caregivers (<http://www.choc.org/cancer/resources/>)
- Ambulatory Care Services (<http://www.choc.org/video/outpatient-services-kathy-kolodge/>)

Introducing Monica Lee, RD



Monica Lee, RD

*"My name is **Monica Lee**. I'm a registered dietician, and my special interest is oncology nutrition. Cancer treatment is tough on our bodies, but a healthy diet can help repair your body by supporting your immune system, building muscle, and increasing circulation."*

Monica Lee - Nutritionist, RD / Monica is currently a Wellness Coach / Human Resource Specialist at NBCUniversal. She is a competitive triathlete, has coached and played college athletics, and has designed 'active lifestyle' (exercise and nutrition) programs for individuals ranging from pro-athletes to survivors dealing with a wide range of illnesses.

Introducing Jenee Areeckal, POSW



Jenee Areeckal, POSW

Jenee, a three-time cancer survivor and an amputee due to osteogenic sarcoma, knows what it is like to live through and be treated for cancer as a teen and young adult. Today she uses her story to inspire her patients and families both during and after treatment. She is proof that life after cancer can be wonderful and fulfilling.

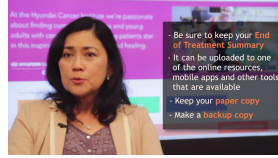
"I hope that by seeing me work, patients have hope that it is possible to survive and thrive after cancer."

*"My name is **Jenee Areeckal**. I'm a pediatric oncology social worker. I am a two time AYA cancer survivor. I had osteogenic sarcoma when I was 15, and I had ovarian cancer when I was 38. I've been taking care of teens with cancer for about 8 years. It's been my life's passion to help them navigate through not only their treatment, but also post-cancer survivorship. It's also very important for me to help educate patients to become strong survivors."*



your treatment and all the recommendations for your surveillance. Nowadays, there are many online resources, mobile apps, and other tools through which you can upload your treatment summary. We strongly recommend that you keep your paper copy, and make sure that you have a backup copy of some kind. And, if you do lose your End of Treatment Summary, you can always call your treating institution and ask for another copy.

Having the End of Treatment Summary will allow you to communicate clearly to your next doctor exactly what you have been through and the recommendations for your follow-up and surveillance.



HOW DOES THE END OF TREATMENT SUMMARY HELP SET GOALS FOR FUTURE HEALING?

It is always a great idea for survivors to set goals for their wellness. The End of Treatment Summary provides a list of possible complications and side effects that you may encounter. It also lists the recommendations for your appropriate surveillance. As a patient, it's a good idea for you to make sure that you have overcome whatever side effects you may have incurred during your treatment. If the side effects persist, then you can set goals that will help you to overcome them.

What Does "Cumulative Dose" Mean and How Can it Affect Future Health?

Cumulative dose refers to the total dose of specific chemotherapy agents that you have received from the beginning to the end of your treatment. In general, the higher the cumulative dose, the higher the possibility of certain side effects. For example, there is a chemotherapy agent known as anthracyclines that may cause problems with the heart. The higher the dose of this drug, the higher the chances that we may have problems with heart function.

It is important for you to know the dose and location of radiation, because the possible effects that can occur will depend on the area that has been irradiated. For example, if a person receives radiation to the brain, he may develop learning disabilities, or there may be a small possibility of developing a different kind of cancer in the future.



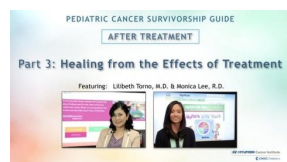
To Learn More:

- National Cancer Institute: Radiation Therapy & You (<http://www.cancer.gov/publications/patient-education/radiation-therapy-and-you>)
- Late Effects of Treatment for Childhood Cancer (<http://www.cancer.gov/types/childhood-cancers/late-effects-hp-pdq#section/all>)
- Heart Problems Following Treatment (<https://childrencyologygroup.org/index.php/organs/heartproblems>)

After Treatment (2)

Healing From the Effects of Treatment

Mitigating the effects of treatment means decreasing the effects of treatment. This could be accomplished using medications or other alternative treatments such as meditation, yoga, aromatherapy, physical therapy, and many other options.



([https://vimeo.com](https://vimeo.com/149316576)

/149316576)

WHAT CAN BE DONE TO REDUCE NAUSEA?

Hopefully, the worst of your nausea is over now that you have completed your therapy. It should keep getting better as the days go by. There are many medicines that can be prescribed to help decrease nausea, and there are also many alternative options that to explore, such as aromatherapy, biofeedback, acupuncture, psychotherapy, and others.

To Learn More:

- National Cancer Institute: Complementary and Alternative Medicine (<https://www.cancer.gov/about-cancer/treatment/cam>)
- Office of Cancer Complementary and Alternative Medicine (<https://cam.cancer.gov/>)

SIDE EFFECTS THAT MAY FOLLOW RADIATION

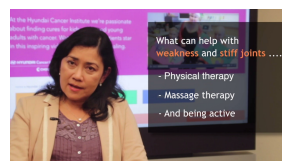
Depending on the body part that's been irradiated, the effects that may follow will vary. For example, if the lungs were irradiated, this may result in a shortness of breath. The corresponding treatment will depend on the symptom you have. If you're feeling side effects from your irradiation, it's very important to talk to your doctor because certain medications may be prescribed to help you.

To Learn More:

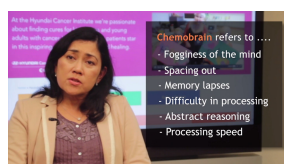
- National Cancer Institute: Radiation Therapy Side Effects (<https://www.cancer.gov/about-cancer/treatment/types/radiation-therapy>)
- Lung Health Post-Treatment (<https://www.childrenscologygroup.org/index.php/organs/lunghealth>)

OTHER POTENTIAL SIDE EFFECTS FOLLOWING TREATMENT

Weakness and stiff joints are common problems after cancer therapy. Physical therapy, massage therapy, and being active are helpful ways to alleviate these symptoms.



What is Meant by "Chemobrain"?



"Chemobrain" refers to symptoms of fogginess of the mind, spacing out, memory lapses, or difficulty in processing or abstract reasoning. All of these may result from chemotherapy or radiation therapy.

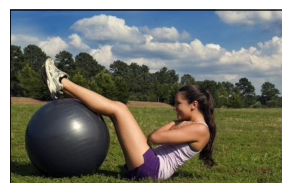
There are now new methods called 'cognitive rehabilitation' that utilize a series of tests and workshops to help rehabilitate or retrain the brain. Along with that, it is very important to live a healthy lifestyle, eat a healthy diet, and be active to help stimulate your brain.

To Learn More:

- Chemo Brain (<http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/chemotherapyeffects/chemo-brain>)
- An Overview of Chemotherapy-Related Cognitive Dysfunction (<http://www.ncbi.nlm.nih.gov/pubmed/25224480>)

Body Image After Treatment

Depending on the type of treatment that a person received – such as surgery that includes amputation, for example – there can be a high impact on a person's body image. Certain medications received, like steroids, can promote excessive weight gain, which can also impact body image. Therefore, it is very important for the patient to seek counseling so that healthcare providers can provide coping strategies to help the patient adjust to their 'New



Normal'.

Photography: CDC/Amanda Mills

Amongst our cancer survivors at CHOC, we've noted that about 20% develop significant weight gain. Diet and exercise is the most important thing that a patient can do to decrease or maintain their weight.

To Learn More:

- Children's Oncology Group: Weight Gain or Weight Loss (<https://childrensoncologygroup.org/index.php/weightgainorweightloss>)
- National Cancer Institute: A New Normal (<http://www.cancer.gov/about-cancer/coping/survivorship/new-normal>)

Feelings of Sadness or Loneliness



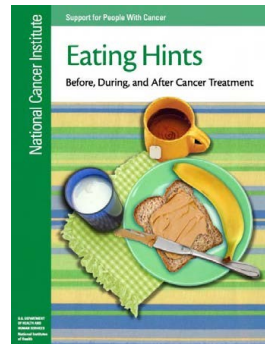
Dr. Torno, "It is normal to feel depressed or lonely after treatment. When you go through your cancer journey, it is normal for there to be some degree of grieving the loss of time, the loss of school, the loss of friends, and the loss of health.

Being with friends and family who understand what you've been through is really important. These are the people who can help you to move through to the other side of your loneliness and your feelings of sadness."

Learning About a Healthy, Post-Cancer Diet

After treatment, your body needs to recover. Your body now may not be at 100% of what it was before cancer, but what it is now will become your "New Normal". Your "New Normal" will be your optimal health after treatment. There are many different treatments and many different diets, so there is no one size that fits all. Some of the resources available to you are www.choosemyplate.gov (<https://www.choosemyplate.gov/>) , as well as your hospital's website.

Monica, "My advice is to consult with a Registered Dietician to create a menu and diet plan specific to your child's needs. After treatment, your body may not be able to tolerate all foods. The type of diet that you should aspire to eat is 'My Plate.' The 'My Plate' diet consists of half a plate full of fruits and vegetables, one fourth of whole grains, one fourth of lean protein, and a small side of dairy that has 2% or less fat. You can also incorporate healthy fats, which consist of nuts, salmon, olive oil, and avocado, to name a few. A good place to learn about the 'My Plate' diet is www.choosemyplate.gov (<https://www.choosemyplate.gov/>) ."



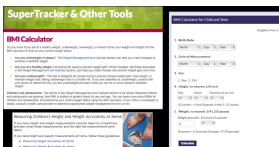
This guide from the National Cancer Institute is also a great resource:

Eating Hints: Before, During and After Cancer

(<https://www.cancer.gov/publications/patient-education/eatinghints.pdf>)

Treatment

(<https://www.cancer.gov/publications/patient-education/eatinghints.pdf>)



WHAT DOES BMI MEAN?

BMI is Body Mass Index, which is the relative amount of muscle and fat in the body as determined by your height and your weight. BMI is used to determine whether your child is a healthy weight, underweight, or overweight. If your child is overweight, it increases their risk for diseases such as obesity and diabetes. Being overweight can also increase the risk of cancer recurrence.

To Learn More:

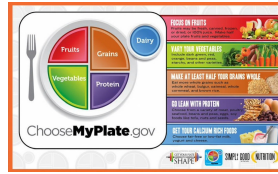
- Calculate Your Child's or Teen's BMI (<https://nccd.cdc.gov/dnpabmi/Calculator.aspx>)
- Choose My Plate SuperTracker and BMI Calculator (<https://www.choosemyplate.gov/tools-supertracker>)
- How To Measure Children's Height & Weight Accurately At Home (http://www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/measuring_children.html)

Which Foods to Avoid

There are a few good ways to think about foods you should avoid. First, when looking at a packaged item, look at the ingredients and see if you can read them and pronounce them. If they look like they came out of a chemistry set, then you probably shouldn't put them in your body. If it doesn't look like something your great-grandmother would recognize, then you should probably think twice about putting it in your body.

In general, you want to reduce fried foods such as French fries and chips, as well as limit red meats, which include beef, pork, and lamb. Lastly, you want to limit the two S's, which are foods that are high in Salt and Sugar. This includes sugary drinks and sodas. Instead, stick to water, milk that is 2% fat or less, or 100% fruit juice. As a rule, always try to bring the best whole foods into your kitchen. There are great recipes on www.choosemyplate.gov (<https://www.choosemyplate.gov/>) for kids and families.

Ultimately, it's you who determines whether you want to live a healthier, longer life. One way you can look and feel better is by putting healthier nutrition into your body.



To Learn More:

- How Food Labels Help Consumers Make Healthier Choices (<http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm094536.htm>)
- Healthy Recipes from ChooseMyPlate.gov (<https://www.choosemyplate.gov/recipes-cookbooks-and-menus>)

Get Moving and Set Exercise Goals



Photography: CDC/Amanda Mills

It's important for your child to exercise to increase muscle strength, increase circulation, increase their focus for learning, boost energy levels, as well as help them to sleep better. Your child should exercise every day, in the morning, if possible, to jumpstart their metabolism. Exercise will increase their muscle and bone strength, and can elevate mood and energy levels to help them feel at their best. Ideally, your child would build up to one hour of exercise per day.

I recommend meeting with your doctor or registered dietician to set exercise goals. A good way to create exercise goals is to make them SMART.

Make your exercise goals SMART...

- **S**pecific
- **M**easurable
- **A**ttainable
- **R**ealistic
- **T**imely

By setting and achieving your new exercise goals, you'll get to your "New Normal". Optimizing your "New Normal" requires attention to diet, exercise, and emotional health. All of these things are important for a long, healthy life.

To Learn More:

- What You Can Do To Get Your Child Active (<http://www.cdc.gov/physicalactivity/basics/adding-pa/activities-children.html>)
- Physical Activity Tracker from ChooseMyPlate.gov (<https://www.choosemyplate.gov/physical-activity>)

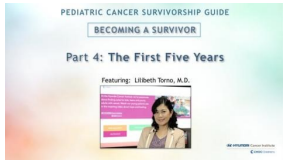
First 5 Years (1)

The First 5 Years

WHY THE FIRST FIVE YEARS IS CONSIDERED AN IMPORTANT MILESTONE

Dr. Torno, "The chances that your cancer will reoccur are highest in the first two years after stopping your treatment. The farther away you are from the end of treatment, the smaller the chances are that your cancer will come back. That is why doctors set a 5 year goal in your cancer journey."

Follow-up Care After Cancer Treatment
<p>Key Points</p> <ul style="list-style-type: none"> Follow-up cancer care involves regular medical checkups that include a review of a patient's medical history and a physical exam. A key purpose of follow-up care is to check for recurrence (the return of cancer in the primary site) or metastasis (the spread of cancer to another part of the body). Follow-up care is individualized based on the type of cancer, the type of treatment received, and the person's overall health, including possible cancer treatment-related problems. There are clinical trial specialists in long-term follow-up cancer care for adult and pediatric cancer survivors. NCC does not have guidelines for follow-up care, but some organizations do provide these resources.



(<https://vimeo.com/149316555>)

FOLLOW UP DURING THE FIRST 5 YEARS

The follow up for the first 5 years will depend on your cancer diagnosis. You will normally be seen by your doctor at frequent intervals in the first years, and then ongoing check-ups will be gradually spaced out. There will be recommendations for blood tests and imaging studies depending on your diagnosis and treatment. During this time we also ensure that you're recovering from all possible complications that may have been incurred during your treatment.

To Learn More:

- National Cancer Institute: Follow-up Care After Cancer Treatment (<https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care/follow-up-fact-sheet>)
- ASCO Cancer Treatment Summaries and Survivorship Care Plans (<http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>)

Can Cancer Come Back?

It is important for you to keep your schedule of check-ups so that your doctor will be able to detect any further complications that may happen in the future. Your doctors also want to make sure that you are recovering well from past complications that you may have undergone. Even if you move or go out of state, make sure that you comply with your doctor's recommendations for your follow-up.

Recurrence is when your cancer comes back. The chances of recurrence in the first 5 years will depend on your cancer diagnosis. However, we know that the chances of recurrence are highest in the two years after you stop treatment. It is important to find any recurrence of cancer early so that we can appropriately treat the disease early enough that it doesn't cause more damage to your body.

Dr. Torno, "At the end of 5 years, the chances of recurrence will be much smaller. The farther away we are from the end of your treatment, the lower the chances are that your cancer will come back."

To Learn More:

- Children's Oncology Group: Relapse or Recurrence (<https://childrensoncologygroup.org/index.php/relapse>)

Where Cancer Can Return

Doctors define recurrent cancers by where they develop. The different types of recurrence are:

- **Local recurrence.** This means that the cancer is in the same place as the original cancer or is very close to it.
- **Regional recurrence.** This is when tumors grow in lymph nodes or tissues near the place of the original cancer.
- **Distant recurrence.** In these cases, the cancer has spread (metastasized) to organs or tissues far from the place of the original cancer.

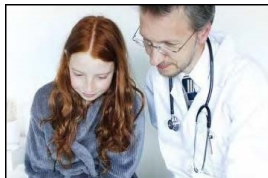
Local cancer may be easier to treat than **regional** or **distant cancer**. But this can be different for each patient. Talk with your doctor about your options.

REMAINING VIGILANT FOR SYMPTOMS OF RECURRENCE

It's important for you to remember the original symptoms that you've had. Whether it was headaches, fever, fatigue, or a lump in the body – any changes that you experience **HAVE** to be reported to your doctor immediately.

PARTICIPATING IN RESEARCH

Dr. Torno, *"Every cancer survivor is a researcher. As you communicate your treatment and what you have been through, your doctors will continue to learn and use this knowledge to treat the patients who follow you. So, don't stop communicating – your doctors always learn and adapt treatment based on the knowledge that they gain from you!"*



WHAT IS 'MENTORING' AND HOW CAN IT HELP?

Mentoring is a process by which you share your experiences with another cancer patient who is currently going through what you have already gone through. By doing this, you can empower them. You give them hope and you strengthen them for what lies ahead. You can mentor other patients by volunteering at your treating hospital or other hospitals, or you may participate in a community, or even in an online community.

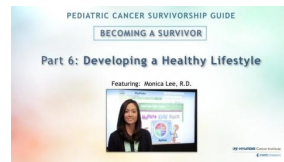
To Learn More:

- Organizations & Resources to Support Young Cancer Patients (<https://www.cancer.gov/types/aya>)
- 4th Angel – Patient & Caregiver Mentoring Program (<http://www.4thangel.org/>)
- Cancer Connects Volunteer Mentor Program (<http://www.cancerconnects.org/volunteerMentorProgram>)

First 5 Years (2)

Developing a Healthy Lifestyle

(*Please note that this is the same content as in After Treatment 2. We've included it in both segments because there may be a long passage of time between review of After Treatment and The First 5 Years, and it's important to remember that diet and exercise are key during both of these phases.)



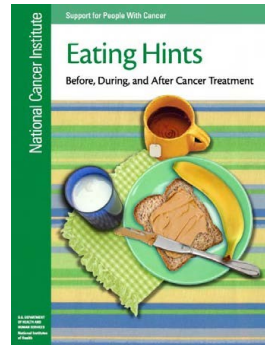
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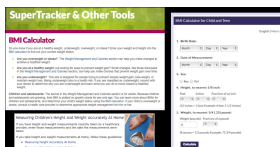


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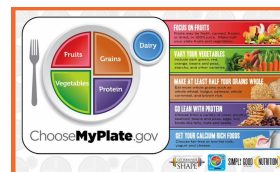
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- Choose My Plate SuperTracker and BMI Calculator (<https://www.choosemyplate.gov/tools-supertracker>)
- How To Measure Children's Height & Weight Accurately At Home (http://www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/measuring_children.html)

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To Learn More:

In general, you want to reduce fried foods such as French fries and chips, as well as limit red meats, which include beef, pork, and lamb. Lastly, you want to limit the two S's, which are foods that are high in Salt and Sugar. This includes sugary drinks and sodas. Instead, stick to water, milk that is 2% fat or less, or 100% fruit juice. As a rule, always try to bring the best whole foods into your kitchen. There are great recipes on www.choosemyplate.gov (<https://www.choosemyplate.gov>) for kids and families.

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Get Moving and Set Exercise Goals



Photography: CDC/Amanda Mills

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I recommend meeting with your doctor or registered dietician to set exercise goals. A good way to create exercise goals is to make them SMART.

Make your exercise goals S M A R T...

- Specific
- Measurable
- Attainable
- Realistic
- Timely

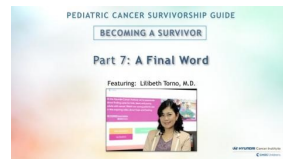
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To Learn More:

- What You Can Do To Get Your Child Active (<http://www.cdc.gov/physicalactivity/basics/adding-pa/activities-children.html>)
- Physical Activity Tracker from ChooseMyPlate.gov (<https://www.choosemyplate.gov/physical-activity>)

A Final Word...

Dr. Torno, *"The most important thing that I would say to a parent and their child after the 5 year mark is to be encouraged and keep going! Share your story! You can help other people, and this is how we learn from each other. All of your knowledge becomes our knowledge – this is how we encourage and empower one another."*



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(<https://vimeo.com>)

Journey to Wellbeing



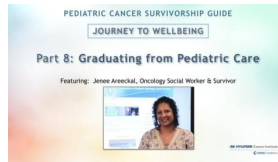
Graduating From Pediatric Care

WHEN IS IT TIME TO GRADUATE FROM PEDIATRIC CARE?

When you graduate from the pediatric care team depends on the institution that you come from. Each institution is different. Sometimes the graduating age is 21, and sometimes it's older. What you need to know to switch over from the pediatric specialist to the adult specialist depends on what kind of side effects you've had. Besides having your normal primary care doctor (you should always have one of those), you would also need to know what specialties are entailed depending on the side effects of your treatment.

To Learn More:

- Children's Oncology Group Survivorship Guidelines (<https://childrensoncologygroup.org/index.php/survivorshipguidelines>)
- Treatment Side Effects (<https://childrensoncologygroup.org/index.php/treatmentsideeffects>)



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Your Follow-up Care Plan
 Once you're done with cancer treatment, you should receive a follow-up cancer care plan from your doctor. The National Cancer Institute and other cancer organizations recommend this document for people who have finished treatment. The details of your plan will depend on the type of cancer and type of treatment you had, along with your overall health. It is usually different for each person. In general, survivors return to the doctor every 3 to 4 months at first, and once or twice a year after that. At these visits, your doctor may give you a physical exam along with blood tests and other follow-up tests that are necessary.
 For follow-up care, you may see the same doctor who treated you for cancer. Or you may decide to go to your primary care doctor. This is something you can discuss with your health care team. Your oncologist should give you a written summary of your treatment. Keep this with you to share with your primary care doctor and any other doctors you see. Many people keep this along with their medical records in a folder or binder. This keeps any tests about your treatment well always in the same place. Types of health information to include may be:

THE IMPORTANCE OF THE FOLLOW-UP PLAN

Jenee Areecal, "It is very important to keep in touch with the follow-up plan that has been given to you during long-term survivorship. As a cancer survivor, I've had to make sure that I keep in touch with my doctors on a yearly basis. Besides the oncologist who I've had, I'm followed by both a cardiologist and an endocrinologist to track my long-term side effects."

To Learn More:

- Your Follow-up Care Plan (<http://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>)
- Facing Forward – Life After Cancer Treatment (<http://www.cancer.gov/publications/patient-education/life-after-treatment.pdf>)

THE ROLE OF THE PRIMARY CARE PHYSICIAN

The role of a Primary Care Physical (PCP) is the point person. That's the person you would go to for regular follow-ups, whether it's a flu shot, a cold, or a cough. The PCP would be able to help you navigate to see the specialists who you need to see. The best way to pass on your medical care to these doctors is to be able to personally inform them about your care and then also provide them with a copy of your long-term survivorship packet.



Managing Stress, Fatigue, and School

IS IT NORMAL TO BE STRESSED AFTER CANCER TREATMENT?

Follow-up Care After Cancer Treatment
Key Points:
 • Follow-up cancer care involves regular medical checkups that include a review of a patient's medical history and a physical exam.
 • A key purpose of follow-up care is to check for recurrence (the return of cancer in the primary site) or metastasis (the spread of cancer to another part of the body).
 • Follow-up care is individualized based on the type of cancer, the type of treatment received, and the person's overall health, including possible cancer treatment-related problems.
 • There are clinics that specialize in long-term follow-up cancer care for adult and pediatric cancer survivors.
 • NCI does not have guidelines for follow-up care, but some organizations do provide these resources.

Dr. Sender, "Is it normal to be stressed out after cancer treatment? Yes. Some patients have no stress, and some patients have excessive stress – it really depends on the individual. Sometimes it's just the realization that therapy has ended, and now you have time to think about what you've been through, and what you still have to go through to get back to wellness. Please, if you are experiencing stress, come in and talk to your healthcare professional about it – we have many ways to help you."

We believe that every single person has a little bit of

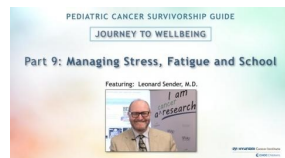
stress – that's okay. Excessive amounts of stress are bad for you, and don't allow healing to occur. You really want to take care of what it means to be very stressed, and part of that involves being open about and acknowledging what the stress is really about.

MANAGING STRESS AFTER CANCER TREATMENT

One of the ways you can manage stress is to vocalize. Talk about your stress – talk to your family, to your friends, and your healthcare professionals. Other ways to manage stress are to exercise, get involved in meditation, starting to practice yoga, or pilates, or some other activity that allows your body and mind to come together to heal.

To Learn More:

- Psychological Stress & Cancer (<http://www.cancer.gov/about-cancer/coping/feelings/stress-fact-sheet>)



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LOW ENERGY AFTER TREATMENT



After cancer treatment, it's very common to have reduced energy levels. In fact, most of the patients do for quite a while. What happens over time is that they suddenly realize that their energy levels have returned to normal and they're not feeling tired anymore. There's a period of time after chemotherapy where the body is still recovering from the effects that the chemotherapy had on its system. It's normal, and you have to work through it.

The best way to recover from being so tired is, paradoxically, to do something – to exercise, to push your body a bit so that you retrain your body. It may take you 3 months, 6 months, or a year before you're back, but you will come back.

To Learn More:

- General Info About Cancer Treatment & Fatigue

(<https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq#section/all>)

- Managing Fatigue (<https://childrensoncologygroup.org/index.php/fatigue>)

GOING BACK TO SCHOOL

There are many challenges in going back to school. One of them is how you do with your school work. We work with your teachers to help them understand exactly what you're capable of doing, what therapy you've had, and what the next stages are for you.

The second part is how you integrate back to your friends. How do you make sure that you get back into your social circumstances, and how do you catch up with the work that you couldn't do because you were sick? We have school integration programs that work with you, your teachers, and your friends to make sure that they understand exactly where you've been.

To Learn More:

- Children's Oncology Group: Challenges in School

(<https://childrensoncologygroup.org/index.php/one-year-off-treatment-and-beyond>) and Learning Problems After Treatment (<https://childrensoncologygroup.org/index.php/school-support/learning-problems-after-treatment>)

- CHOC Children's Student Education and Support Program (SEAS) (<http://www.choc.org/cancer/support-services/>)



Teen and Young Adult Issues

WHAT IS HEALTH LITERACY?

Dr. Sender, "We think of health literacy as something that allows you to understand what therapy you've been

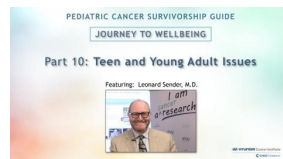
through, what therapy meant to you – the words, the terms, the terms that describe your actual cancer – and also what it means for you in terms of getting back to wellness. We want you to know what it is that you need to look out for.”

FINDING REPUTABLE SOURCES ON THE WEB

How do you know if you've gone to a credible site on the internet? Often, you don't. There are really good sites from reputable institutions like the National Cancer Institute, the American Cancer Society, and the Leukemia and Lymphoma Society, to name a few.

To Learn More:

- Cancer Information on the Internet (<http://www.cancer.org/cancer/cancerbasics/cancer-information-on-the-internet>)
- Evaluating Online Sources of Health Information (<https://www.cancer.gov/about-cancer/managing-care/using-trusted-resources>)



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A Few Suggested Sites:

- National Cancer Institute (<https://www.cancer.gov/>)
- Children's Oncology Group (<https://childrensoncologygroup.org/>)
- American Cancer Society (<http://www.cancer.org/>)
- Leukemia and Lymphoma Society (<http://www.lls.org/>)

ALCOHOL AND ITS IMPACT ON RECOVERY

Drinking alcohol can affect a teen's recovery after cancer because the alcohol itself can damage the liver. Many of the chemotherapy drugs that we use to treat cancer in this age group can affect the liver's functioning. If you add alcohol, it may inhibit the liver from working properly. This is why we strongly caution against alcohol use, because it really can do some harm.

How can teens know if alcohol is going to interfere with their medications? It's very important that they ask their team of healthcare professionals. Before you go back to that new lifestyle that's similar to your old lifestyle and start drinking again, really talk to your doctors. Find out from your doctors and pharmacist whether drinking any alcohol may affect your liver and therefore your health.

To Learn More:

- Straight Talk – Does Alcohol Affect My Cancer? (<https://straighttalk.chocchildrens.org/young-adult-cancer/does-alcohol-affect-my-cancer/>)

CAN SMOKING MARIJUANA AFFECT A TEENS RECOVERY?

The answer is that we don't really know. A reason that people use marijuana is often because of nausea during chemotherapy. The chemotherapy is done and the nausea will be over, so what we tell patients is that we don't believe that it's safe to use a product that we don't fully understand or know what the long-term implications might be for someone who's been through chemotherapy. Whenever possible, we say to avoid it.

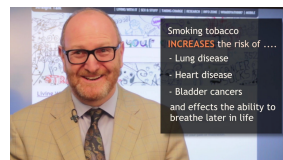
AVOID smoking marijuana -

There is not enough known about the drug and what the long-term implications might be, especially for anyone who has been through chemotherapy.

TOBACCO AND HEALTH

We've known since the 1960's that smoking tobacco increases your risk of getting lung disease, heart disease, bladder cancers, and negatively impacts your ability to breathe later on in life. Smoking tobacco is never a good idea, and we recommend not using it.

Will tobacco use put you at risk for future cancers? The answer is most likely yes. We know that tobacco on its own increases people's risk of cancer. If you've already had cancer and been through therapy that's damaged your normal tissue and increased your risk for secondary cancer, adding tobacco massively increases your risk.



As for E-cigarettes and health, it's still early on and a lot of research is being done right now, but nicotine in the amount that's given in E-cigarettes is not healthy for someone - especially if they've had chemotherapy that may have affected their liver. We don't know the long-term consequences of using electronic cigarettes. We tell patients not to use them, as you may be further damaging your body after it's already sustained damage.

To Learn More:

- Smoking in Cancer Care (<https://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/smoking-cessation-pdq#section/all>)
- Use of E-Cigarettes Growing Among Teens (<https://blog.chocchildrens.org/use-of-cigarette-like-devices-growing-among-teens/>)

TAKING SOMEONE ELSE'S PRESCRIPTION DRUGS

We're often asked if you can take someone else's prescription medication. The answer is no. Every time we prescribe a drug, we prescribe it to you as an individual, using out knowledge of your medical condition. Using someone else's medication not only can be dangerous, it can be fatal.

To Learn More:

- What Parents Must Know About Prescription, OTC Drug Abuse (<https://blog.chocchildrens.org/what-parents-must-know-about-prescription-otc-drug-abuse/>)

HOW CANCER TREATMENT CAN AFFECT A BOY'S REPRODUCTIVE HEALTH

Cancer treatments can destroy the sperm and can destroy the testes function to make sperm. Often in the beginning, we do sperm banking before treatment and save the sperm for later use. It requires that the sperm be frozen and stored for many years. We can test someone to make sure that their sperm has come back and they're functioning normally, and if that doesn't happen, we'll let the patient know that they need to keep up with paying the yearly fee to keep their sperm frozen until they really need it.

In terms of testosterone, we're just learning about how all chemotherapy can affect a male's ability to have testosterone, and testosterone is needed for sexual function.

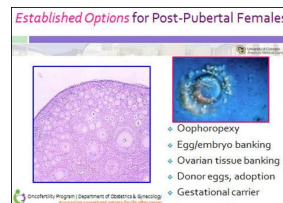


To Learn More:

- Male Health Issues After Treatment for Childhood Cancer (<http://www.survivorshipguidelines.org/pdf/malehealthissues.pdf>)
- Cancer Therapy's Affect on Male Reproductive System and Fertility Option (<https://childrensoncologygroup.org/index.php/hormonesandreproduction/malereproductivehealth>)
- Fertility Concerns and Preservation for Men (<http://www.cancer.net/navigating-cancer-care/dating-sex-and-reproduction/fertility-concerns-and-preservation-men>)

HOW CANCER TREATMENT CAN AFFECT A GIRL'S REPRODUCTIVE HEALTH

Cancer treatment can permanently damage the ovary. It can make the ovaries infertile, so that there's an inability to have children later on. The consequence of damaging the ovaries is that they no longer produce normal hormones, and if they don't produce normal hormones that affects fertility. Sometimes treatment doesn't kill the ovary instantaneously, but it kills it over time. Therefore, a girl can lose her ability to have children over time, because she'll have a highly accelerated rate of entering into menopause. It's very important for any girl to talk to their oncologist and their adolescent gynecologists. Working together, your team can determine whether your ovary function is normal after your treatment.



To Learn More:

- Female Health Issues After Treatment for Childhood Cancer (<http://www.survivorshipguidelines.org/pdf/FemaleHealthIssues.pdf>)
- Effects of Children's Cancer Treatment on Female Reproductive Health (<https://childrensoncologygroup.org/index.php/hormonesandproduction/femalereproductivehealth>)
- Preserving Fertility in Adolescent Cancer Patients (<https://blog.chocchildrens.org/preserving-fertility-adolescent-cancer-patients/>)

PREVENTING SEXUALLY TRANSMITTED DISEASES

All teens should be concerned about sexually transmitted diseases. The concept of using a condom still holds – because you've had cancer and survived it, that doesn't mean that you can get AIDs, or gonorrhea, or syphilis, etc. We highly recommend that teens engage in safe sex practices, be smart about their sexual activity, and use condoms.

To Learn More:

- How STDs Affect the AYA Population (<http://www.cdc.gov/std/life-stages-populations/adolescents-youngadults.htm>)



Independence



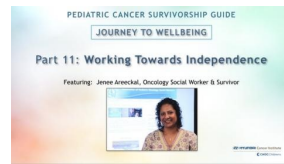
TAKING LEADERSHIP IN YOUR OWN CARE

Jenee Areeckal, “*The relationship between teens and parents changes as they get older – teens become adults. At this point, it’s important for them to take leadership in their own care, and I tell my teens that there will be a time when they won’t be with their parents all the time and so they need to learn to be an independent person as well as a good survivor.*”

“The way that we can help teens to know about their cancer and their follow-up treatment before they go to college is through education. With the teens that I have mentored in the long-term survivorship program, I always tell them to know what their diagnosis is, what their side effects are, and I tell them that if they ever feel any difference in their body to use the medical resources on campus and to let their primary care doctor know and have it checked out immediately.”

To Learn More:

- How Parents Can Help Teens Manage Their Healthcare (<http://blog.chocchildrens.org/parents-can-help-teens-manage-health-care/>)
- Young Adults Transitioning to Adult Focused Care (<https://childrensoncologygroup.org/index.php/young-adults-transitioning-to-adult-focused-care->)
- For Caregivers: When Someone You Love Has Completed Cancer Treatment (<https://www.cancer.gov/publications/patient-education/someone-you-love-completed-cancer-treatment.pdf>)



(<https://vimeo.com/149316473>)

For long-term survivorship, you are able to get or compile a folder that describes your diagnosis, your treatment, and what your side effects are. What I recommend that my young adults do is to give a copy of that document to their primary care doctor or whatever doctor they see while they’re in college. The person who is most responsible for your survivorship is YOU. You need to be the advocate and the leader in your own care.

To Learn More:

- Straight Talk Quiz: Are you ready to take charge of your own healthcare decisions? (<http://straighttalk.chocchildrens.org/young-adult-cancer/quiz-ready-to-take-charge/>)
- Long-term Follow-up Care and Treatment Summary (<https://childrensoncologygroup.org/index.php/long-term-follow-up-care>)

STAYING IN TOUCH

Jenee Areeckal, “*Your pediatric oncology social workers and doctors would love to hear from you. They’ve shared a journey with you, and so your updates only help them to see where you’ve gone and how far you’ve come. For them, that brings immense satisfaction and gratitude.*”

To Learn More:

- Healthy Living After Cancer (<http://www.cancer.net/survivorship/healthy-living>)

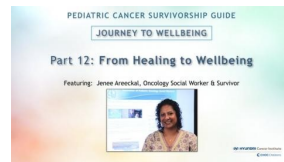
From Healing to Wellbeing

Now that you have conquered cancer, it is important for you to learn to adjust back into society. You’ve gone through a huge shift and change in your life and still been able to manage this new life of being a cancer survivor after everything that you’ve gone through, and going back to what used to be normal for you means that you’re going to have to find a way to merge who you used to be with who you are now and find a balance between the two so that you can get busy living!

Jenee Areeckal, “*The things that I would hope that you would pay the most attention to would be your emotional wellbeing, your physical wellbeing, and also your follow-up care.*”

To Learn More:

- A New Normal (<https://www.cancer.gov/about-cancer/coping/survivorship/new-normal>)



(<https://vimeo.com/149316465>)



NEVER SAY 'NEVER'!

Jenee Areeckal, "Prior to cancer, being an athlete was my passion. When I was diagnosed with osteosarcoma and lost my leg, I never thought that I could still do sports. When I started college, I took a beginning class thinking that I couldn't swim. When I got into the pool, I realized that I could – it was just a matter of learning this new way of swimming. This is our 'New Normal'."

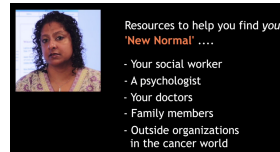
As an amputee, playing tennis is another sport that I have become very passionate about. I have realized that I can play tennis. I didn't think that I could play tennis. In my situation, I'm able to play tennis in a wheelchair, and that is very empowering. I can play tennis with any able-bodied person. Also, skiing is something that I thought I needed two legs to do. It turns out that I'm able to use something called a 3-track skier. Before, I thought that I'd never be able to be an athlete as an amputee. It turns out that I could be, can be, and am an athlete, and I enjoy it."

RESOURCES TO HELP YOU FIND YOUR 'NEW NORMAL'

As a patient tries to find their 'New Normal', it is important for them to use outside resources, whether it be their social worker, a psychologist, their doctor, family members, or outside organizations in the cancer world such as Stupid Cancer or the American Cancer Society. Those organizations have great resources where they can connect to other people who have gone through a similar situation to theirs, and can help them to adjust to their 'New Normal' by connecting with other survivors.

To Learn More:

- STUPIDCANCER - Connect (<http://stupidcancer.org/connect/>)
- ACS Cancer Survivors Network (<http://csn.cancer.org/>)



Jenee Areeckal, "I think a way you can find your 'New Normal' is by using something that you're passionate about. For example, in my case it was being an athlete. Find an organization or a resource that can help to get you back into that passion. I connected with the Challenged Athletes Foundation, and that was able to help me get back to my new norm. For you, it might be something like writing and trying to write about your story, so try and see within the cancer world or non-cancer world if you can connect with writers who talk about their stories. That's a way that you would be able to get back into your 'New Normal'."

To Learn More:

- Challenged Athletes Foundation (<http://www.challengedathletes.org/>)
- Resources for Teen Cancer Survivors (<http://www.cancer.net/navigating-cancer-care/teens/resources-teens>)



AN ACTIVE LIFESTYLE MEANS A HEALTHY LIFESTYLE

Nutrition and exercise play a huge role in your long-term goals. A lot of different things have happened in your body – different kinds of treatment, medications, chemotherapy, maybe surgery. After going through that, you really want to make sure that your body is healthy, and give it a good diet and good exercise.

To Learn More:

- Staying Healthy Through Diet and Physical Activity (<http://www.survivorshipguidelines.org/pdf/DietandPhysicalactivity.pdf>)
- Guidelines for a Healthy Lifestyle (<https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>)
- Being Healthy After Treatment Ends (<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/behealthyaftertreatment>)

SETTING LONG-TERM HEALTH GOALS

One long-term health goal you should set is keeping your body healthy. That would entail a good diet and great exercise, which includes exercising your brain, your mind, your soul. Those are all wonderful ways to set and keep long-term goals. Also, include your goals for your career path and for friendships and relationships – get back into society and get back into living! Those are all great goals. You've survived cancer now, why not keep on living? Set goals that set you up to be a great survivor.

To Learn More:

- Healthy Living Guidelines for Cancer Survivors (<http://www.cancer.org/cancer/news/expertvoices/post/2012/04/26/new-healthy-living-guidelines-for-cancer-survivors.aspx>)
- Nutrition and Lifestyle in Cancer Survivors (<https://www.cancer.gov/about-cancer/treatment/side-effects/appetite-loss/nutrition-pdq#section/all>)
- Getting a Wellness Plan (<https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>)

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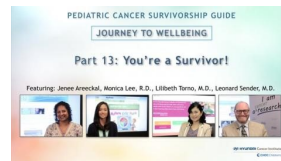
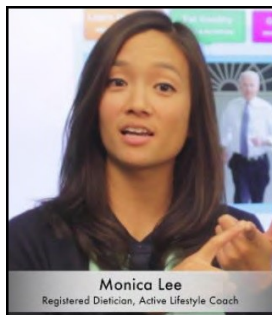
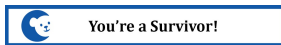
- Facing Forward: Life After Cancer Treatment
 (https://www.cancer.gov/publications/patient-education/life-after-treatment.pdf)



GET BUSY LIVING... YOU'RE PAST THE FIVE YEAR MARK!

Jenee Areeckal, "What I would say to a child who has just past the 5 year mark is, 'Now you need to learn to get busy living. Get back into your friends, get back into your recess, get back into playing and being the fun kid that you are.' It may look different, but you're still normal.

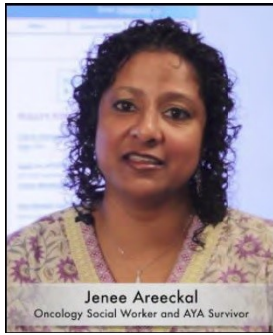
What I mean by 'get busy living' is that I love to lead a healthy, active lifestyle, to get back into society and be a part of my community, and also do sports and have fun, like any other young adult would."



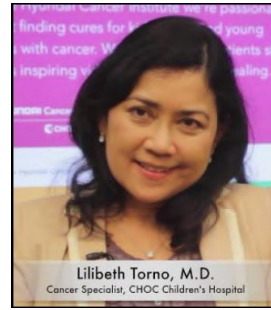
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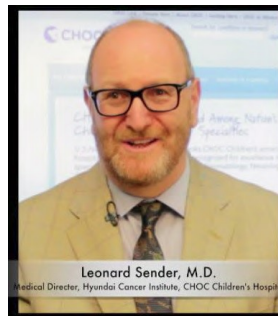
"Optimizing your 'New Normal' consists of diet, exercise, and emotional health. All of these things are important for a long, healthy life."



"Congratulations, you've become a survivor! That entails just giving back – be the great survivor that you can be! Stay in touch with us, because it helps us continue to learn."



"The most important thing that I would say to a parent and their child after the 5 year mark is to be encouraged and keep going! By sharing your story, you can help other people. This is how we learn from each other. All of your knowledge becomes our knowledge, and this is how we encourage and empower one another."



"We get really excited when a child reaches their 5 year mark, because about 98% of the time that means that you've cured your cancer – the initial cancer isn't going to come back. What we want to do is make sure that everyone understands that they still need to be very much engaged with us as their cancer professionals, because the long-term consequences of the treatment that we've done need to be monitored and followed. We need to be engaged, and we need to make sure that survivors understand that. We're really happy for them, and we also want them to start moving on to the next phase of their lives."

