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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:

- **Post Treatment** features Dr. Beatriz Currier, Dr. Doured Daghistani, Dr. Minesh Mehta, Joann Santiago Charles, Oncology Exercise Physiologist, and Karla Otero, RD. This is the segment that you want to focus on immediately after treatment.
- **The First 5 Years** features Dr. Doured Daghistani, Karla Otero, RD, and Joann Santiago Charles, Oncology Exercise Physiologist. This is the segment that you want to focus on for the first 5 years of survivorship.
- **Long-term Survivorship** features Dr. Beatriz Currier, Dr. Doured Daghistani, Dr. Minesh Mehta, and Mari Lourdes Garcia-Martinez, 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. Currier



Beatriz Currier, M.D.

"Hi, I'm Dr. Beatriz Currier and I'm the Medical Director for Cancer Patient Support Services at Miami Cancer Institute. My job is to help you and your family through your cancer journey. Our program addresses the emotional, physical, social and spiritual needs of our cancer patients and their families from the time of diagnosis through active treatment, and after completing treatment into survivorship."

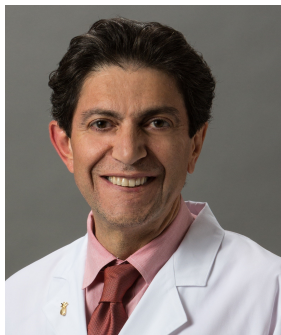
"I want to congratulate you for your bravery and courage and getting through probably one of the biggest hurdles in your life, and encourage you to continue living a healthy life ahead. Undergoing cancer treatment can be one of the greatest challenges you've experienced so far in your lifetime; so celebrate your courage and your strength in completing that hurdle. But the end of treatment is not the end of your cancer experience, and as you transition into survivorship there are many challenges ahead of you still."

Dr. Beatriz Currier, M.D. earned her medical degree from the University of South Florida College of Medicine in Tampa. She completed a general psychiatry residency at the University of Miami/Jackson Memorial Medical Center and completed a clinical fellowship in psychosomatic medicine at Harvard Medical School/Massachusetts General Hospital in Boston.

A Diplomat of the American Board of Psychiatry and Neurology with a subspecialty certification in psychosomatic medicine, Dr. Currier is published widely in the academic press and is a reviewer for several peer-reviewed journals. She has served as a principal investigator on numerous pharmaceutical studies.

Prior to joining Miami Cancer Institute, Dr. Currier was medical director of Sylvester Oncology Support Services, medical director of the Courtelis Center for Psychosocial Oncology and chief of Clinical Psychiatry Services at Sylvester Comprehensive Cancer Center. She also served as division chief of Psychosomatic Medicine in the Department of Psychiatry at University of Miami Miller School of Medicine.

Introducing Dr. Daghistani



Doured Daghistani, M.D.

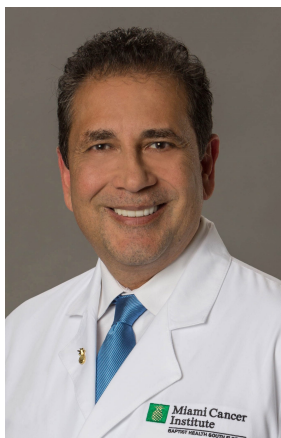
Pediatric hematologist/oncologist **Doured Daghistani, M.D.**, has been elected vice president of the more than 1,400 physicians on the Baptist Hospital medical staff. He served as secretary/treasurer from 2008-2011. He also serves as medical director of pediatric oncology, and chairman of Baptist Children's Hospital Executive Board. He has been on staff at Baptist Hospital since 1992.

Dr. Daghistani received his medical degree from the University of Damascus, Syria, and completed his residency and fellowship at the University of Miami.

"My name is Doured Daghistani, I am the Medical Director of the Pediatric Oncology Department at Miami Cancer Institute. I have been caring for children with cancer for over 30 years."

Dr. Daghistani is Board-certified in pediatrics with a subspecialty in pediatric hematology/oncology.

Introducing Dr. Mehta



Minesh Mehta, M.D.

As deputy director and chief of radiation oncology, **Minesh Mehta, M.D.**, a world-renowned expert in radiation oncology, proton therapy and cancer research, will position Miami Cancer Institute's proton therapy center—the only one of its kind in South Florida and one of fewer than two dozen in the United States—as the region's top destination for this cutting-edge treatment. In March 2015, Baptist Health South Florida signed an agreement with IBA, the world's leading provider of proton therapy solutions for the treatment of cancer, to bring the advanced therapy to the Cancer Institute.

Dr. Mehta joins Baptist Health from the University of Maryland School of Medicine, where he served as medical director of the Maryland Proton Treatment Center in Baltimore and as the university's associate director of clinical research in the Department of Radiation Oncology. He previously held major academic, research and administrative leadership positions at Northwestern University in Chicago and the University of Wisconsin in Madison.

Introducing Karla Otero



Karla Otero, R.D.

Karla Otero has worked at Baptist Health South Florida for 16 years in the areas of clinical nutrition, outpatient nutrition counseling and diabetes education. For the past 9 years, she has focused her efforts on oncology nutrition, most recently as supervisor of clinical nutrition services in the Radiation Oncology department of Miami Cancer Institute. Karla holds a Bachelor of Science in Dietetics and Nutrition from Florida International University, where she is also pursuing her master's degree in the same field. Karla is a Registered Dietitian Nutritionist (RDN) through the Commission on Dietetic Registration and the Academy of Nutrition and Dietetics.

She is a certified diabetes educator through the National Certification Board for Diabetes Educators and a certified specialist in oncology nutrition through the Commission on Dietetic Registration. Karla has participated in numerous community programs across South Florida to help promote healthy eating and disease prevention and has been interviewed by television, radio and local newspaper outlets on similar topics. She actively develops educational materials to help clients increase their knowledge on nutrition, general health and symptom management related to their disease.

Introducing Joann Santiago-Charles, Exercise Physiologist



Joann Santiago Charles

Joann Santiago-Charles joined Miami Cancer Institute at Baptist Health South Florida in 2016 as an oncology exercise physiologist within the Institute's Cancer Patient Support Services department. Joann holds a Bachelor of Science in exercise science, and is pursuing a Master of Science in exercise science and health promotion with a specialization in rehabilitation science, which she will complete in 2017.

She is a certified cancer exercise trainer through the American College of Sports Medicine (ACSM) and the American Cancer Society, and an ACSM Certified Clinical Exercise Physiologist with a level 3 exercise is medicine credential. Joann is certified as a corrective exercise specialist through the National Academy of Sports Medicine and as of December, 2016 a registered yoga instructor through the Yoga Alliance.

"My name is Joann Santiago and I'm the Oncology Exercise Physiologist. I work with the Cancer Patient Support Services, as well as the Survivorship Program. My goal is to help the patient post treatment incorporate exercise back into their daily life."

Introducing Mari Lourdes Garcia-Martinez, Oncology Social Worker



Mari Lourdes Garcia-Martinez

*"My name is **Mari Lourdes Garcia-Martinez**, and I'm the social worker that works with children and adolescents that have been diagnosed with cancer. "*

Mari Lourdes Garcia-Martinez is a licensed clinical social worker with more than 12 years' experience in clinical oncology social work, family & individual counseling, community advocacy and education. Having recently joined Miami Cancer Institute, she has worked at Baptist Health South Florida for the last 10 years to provide our youngest patients and their families with the psychosocial & emotional support, therapeutic services, survivorship guidance and community/financial assistance needed to help navigate a cancer journey.

Throughout her career, Mari Lourdes has worked with children with developmental delays to provide mental health counseling. She developed a mother and children's program for the victims of substance abuse and has provided extensive counseling and support to hospice patients and their loved ones. Mari Lourdes holds a Bachelor of Science in social work with a minor in psychology from Florida International University. She obtained her master's degree in social work at Florida International University in 2004, graduating with honors.



After Treatment



Part 1

After Treatment

What is the "New Normal"?

Dr. Currier, "After completing active treatment, you need to give yourself time to heal and to recover. You're going to feel fatigued and you need to let your body rest, and it's during this time that many patients refer to this as "The New Normal" because your routine in life has changed, your priorities have changed, maybe even your goals have had to change temporarily, but in time you will reestablish your routine, your hobbies, and your activities, and you'll be able to reclaim your life again.

Optimizing your "New Normal" should focus on a whole body approach. So of course, exercise is an important component of it, but you also want to incorporate a healthy diet and drink plenty of water, making sure that you're managing your emotional health and stress and getting plenty of sleep at night."

A patient finds their "New Normal" by learning what their body is capable of doing:

- When you go for a walk, how far can you walk?
- The next day, can you go a little bit farther?
- Does it hurt? What hurts?
- Can you run? Are you able to run a quarter of a mile, a mile?

Finding your new normal doesn't happen instantaneously. It's a process – a process of getting in touch with your body, understanding what you're capable of doing, and always pushing yourself a little bit more, because the further you are from your active treatment the better you're likely to become.

What is the "End of Treatment Summary"?

The **End of Treatment Summary** is an important document that details the cancer treatment summary you've received.

It specifically includes:

- The type of cancer you have
- The staging of the cancer
- Treatment details - surgery, chemotherapy, radiation treatment
- Side effects
- Survivorship Follow-up Care Plan - doctor appointments and follow-up tests (scans, X-rays, and blood tests)

PEDIATRIC CANCER SURVIVORSHIP GUIDE

AFTER TREATMENT

Part 2: The End of Treatment Summary

Featuring: Beatriz Currie, M.D. & Douaid Daghistani, M.D.



Miami Cancer Institute



(https://vimeo.com

/173640557)



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Every patient responds differently to treatment and may experience different types of effects from that treatment. It's important to know the details and the exact treatment that your child had because that will impact their follow-up care. If they received certain doses of a particular chemotherapy, that will direct the physicians in terms of what testing needs to be done, and how frequently they need to be seen in follow-up. That will also influence what we need to monitor for specifically in the future. Cancer Surveillance Guidelines have been established nationally based on cancer type and staging, to ensure that all cancer survivors are being monitored on a scheduled basis.

The **End of Treatment Summary** will contain the name of your doctor and treating institution, your cancer diagnosis, and the treatment that you have received – including any

EXAMPLE OF END OF TREATMENT SUMMARY

surgery, chemotherapy, and radiation. It may list all your ongoing medical concerns, along with ongoing follow-up or surveillance. It is very important for you to know the details of your cancer and your cancer treatment so that your next doctor will have information on possible future tests and symptoms that he or she would need to be aware of.

Treatment Information					
Chemotherapy	Name	Total dose	How often to receive	How long to receive	How often to receive

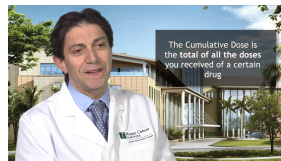
The National Guidelines for an End of Treatment Summary have been published by the National Cancer Institute, the Children's Oncology Group, the American Society of Clinical Oncology, the American Cancer Society, Cancer.net, and other reputable organizations. It is very important that you make sure that you look up these guidelines using reputable organizations as sources, and that if you do have any questions you make sure to discuss them with your doctor.

To Learn More:

- Follow-up Care After Cancer Treatment (<http://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care/follow-up-fact-sheet>)

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.



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://childreoncologygroup.org/index.php/organs/heartproblems>)

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.

Your **"End of Treatment Summary"** should be a lifelong document that you hold onto. Ideally, you'll be given several copies of the document, and we encourage you to scan them and keep them electronically. This should become a part of your medical permanent record, and all of your physicians throughout your life should receive a copy of this.



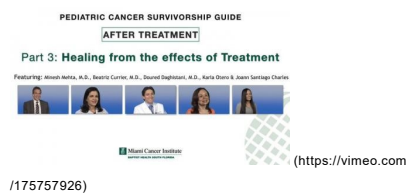
It is always a great idea for survivors to set goals for their wellness. The End of Treatment Summary provides a list of possible complications and side effects that you may encounter. It also lists the recommendations for your appropriate surveillance. As a patient, it's a good idea for you to make 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. Ensuring wellness through healthy diet, physical activity, avoiding smoking - are all behaviors that can help to reduce your risk and enhance your health in the future.

Side Effects That May Follow Radiation

Dr. Mehta, "Radiation therapy is a form of light. It's a form of light that carries a lot of energy which is capable of destroying a tumor, and we can deliver this very precisely with the technologies that we have today, and what that means is for the majority of patients we can put the radiation where it needs to go, that is in the tumor, therefore we can reduce the unnecessary radiation to normal tissues very effectively. The majority of patients get very few side effects because of this, and the majority of side effects are quite mild.



The good news in all of this is once again, as the technology gets better and better, the side effects are fewer and less intense."



The side effects depend on the region of the body that's being treated. For some patients with tumors located in the head and neck, side effects can include: hair loss, difficulty swallowing, and weight loss because they're not able to eat very well. Patients that are treated with tumors in the thorax, chest, abdomen, or pelvis, sometimes can experience fatigue, difficulty eating, and difficulty with their bowel function.

Weakness, fatigue, deconditioning, and stiff joints are common complications in cancer patients. Miami Cancer Institute's program addresses that by ensuring that you're being seen by a physical therapist and an exercise fitness specialist to minimize those types of effects.

To Learn More:

- National Cancer Institute: Radiation Therapy (<http://www.cancer.gov/about-cancer/treatment/types/radiation-therapy>)
- National Cancer Institute: Radiation Therapy Side Effects (<http://www.cancer.gov/publications/patient-education/radiation-side-effects>)

Chemobrain

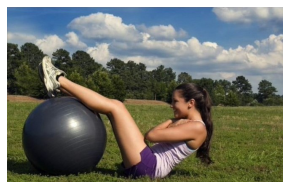
Chemobrain refers to some of the concentration, attention, and memory problems that may develop as a result of certain cancer treatments, specifically some chemotherapies, and with brain irradiation. These concentration and memory problems are treatable. Here at Miami Cancer Institute we provide the resources needed to help you address these problems. Once they have been identified, we use a computerized program to restore your ability to concentrate, focus, and remember things. This will enable us to help you get back on track at school, at work, and in your life.



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



Photography: CDC/Amanda Mills

Unfortunately, weight gain is a common complication seen in pediatric & adolescent cancer survivors. We provide nutritional services and exercise training to help reduce and manage those weight issues. Getting to a healthy weight is very important because being overweight has been associated with an increased risk for recurrent cancers or new cancers. Therefore, it is very important for the patient to seek counseling so that our healthcare providers can provide coping strategies to help the patient adjust to their 'New Normal'.

To Learn More:

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

Certain medications received, like steroids, can promote excessive weight gain, which can also impact body image.

There are two issues with the body when you take a steroid:

1. Your body retains extra fluid.
2. You have an increased appetite.

As you're taking the steroid, your body is swollen. When you stop, your body goes back to its normal configuration.

The surgery can also have long-term effects, in the form of scarring. Some patients may have obvious scars, while others may have unnoticeable scarring, but you will likely have a scar on your body in the area of the surgery. The way you deal with a changed body image is to be prepared for it. Listen to your doctor, their advice will help you through this.

Feelings of Sadness or Loneliness

Dr. Currier, "Many of our cancer patients experience a range of emotions including sadness, anxiety, fear, worry, and depression. The most important thing is to let us know, we can help. We have a team of experts prepared to work with you to help you sort through these feelings. Individual counseling, support groups, and connecting with other cancer patients can markedly help, and just remember, you're not alone."



Getting Healthy After Treatment

Learning About a Healthy, Post-Cancer Diet

Eating healthy is very important before, during, and after cancer treatment. Nutrition plays a very important role in the lives of patients undergoing active treatment and especially in the lives of our long-term cancer survivors. When it comes to childhood cancer survivors, unfortunately children are at a higher risk of developing other conditions such as: heart disease, diabetes, and secondary cancers in relation to treatment. Nutrition in this case is extremely important to keep those risks lower.



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

Eating Hints: Before, During and After Cancer Treatment
(<http://www.cancer.gov/publications/patient-education/eatinghints.pdf>)

Keep in mind that a healthy diet will:

- Speed up recovery
- Help keep the child away from infection during and after treatment
- Help promote optimal growth and development
- Help the child feel and look better



Making the transition from treatment to healing can be challenging. The patient may still be experiencing some side effects from treatment, lack of appetite, nausea, and changes in taste. You have to become creative in offering your child foods that are appealing to them. In general, most children during the healing phase need good sources of protein, carbohydrates, vitamins, minerals, and good hydration. You have to be patient and flexible, to help your child transition into a healthy, nutritious diet.

Proteins

Protein is extremely important. Your body needs protein to heal, to build new tissues, to repair tissues, to build new blood cells and also to boost the immune system.

Good sources of protein include:

- Lean meats
- Poultry
- Fish

Carbohydrates

Carbohydrates are the preferred body's fuel for energy. Your cells need energy to maintain your organs so they can function well.

Good sources of carbohydrates include:

- Fruits and vegetables
- Grains (rice, pasta, bread, cereals)
- Potatoes

Fats

We need to focus on healthy fats. Fats are important because our body can store energy as fat, and also fat can help carry vitamins through the bloodstream.

Good sources of healthy fats include:

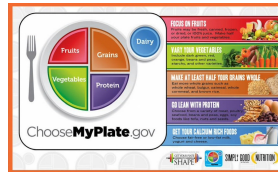
- Vegetable oil
- Avocados
- Nuts and seeds

- Beans
- Peas
- Lentils
- Peanut butter

- Sweet potatoes
- Beans

- Fatty fishes like salmon

You can use **MyPlate** as a guide for a healthy, post-cancer diet. In this website, you'll find the 5 food groups as the building blocks of a healthy diet. It will help you learn how to eat healthy and plan your plate.



You want to fill half of your plate with fruits and vegetables. Fill one quarter of your plate with a lean protein and the other quarter of your plate should be filled with a grain (ideally a whole grain) so you can add the benefit of fiber. Lastly, include a serving of dairy in the form of fat-free/low-fat milk, yogurt, or cheese. These tips should help make a plate that looks colorful, healthy, and well-balanced.

www.ChooseMyPlate.gov (<https://www.choosemyplate.gov/>)

Which Foods to Avoid...

Not every calorie is created equal. You need to focus on the quality of the foods that you're eating. When it comes to cancer prevention, you need to know what foods to avoid.

Many of these foods have cancer causing chemicals that you want to stay away from.

Avoid foods high in added sugar such as:

- Sugary drinks
- Rich desserts

Avoid highly processed meats such as:

- Luncheon meats
- Sausages
- Salami
- Pepperoni
- Bacon

Avoid highly processed foods such as:

- Frozen meals
- Chicken nuggets
- Hot dogs

Your child can still enjoy these foods, but just not on a regular basis.

Start Moving and Setting Exercise Goals

Exercise plays a very important role in cancer rehabilitation specifically because it can prevent the recurrence of second cancers. It can also help to improve the patient's quality of life.

- Exercise helps promote:
- Body image
 - Muscle strength
 - Muscle loss prevention
 - Better sleep
 - Focus
 - Reduced blood pressure, cholesterol, and body weight



Photography: CDC/Amanda Mills

There are a lot of different aspects as to why exercise is beneficial.

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>)



Photography: CDC/Amanda Mills

Joann Santiago Charles, "The goal is to exercise every day for at least 60 minutes. Ideally, if your child can't get to 60 minutes, they can start with whatever they can do. If they start with 10 to 15 minutes and then gradually increase over time, it's a better option than trying to force everything at one time. You can also spread out exercise over the course of the day, so they can do 10 minutes in the morning, 10 minutes in the afternoon, and 10 minutes in the evening, and then gradually build up their endurance. It shouldn't be forced, structured exercise, but more focused around play and making it fun and enjoyable for the child, so that they're willing to participate in it. For a child who just finished cancer treatment, I would say to stay positive, try a little bit each day, and don't be afraid to push and see what they can do. At first it may seem a little scary, but you'll be surprised what you can do if you try a little bit."

The First 5 Years



Part 2

The First Five Years

Why the First 5 Years is Considered an Important Milestone

During those first five years after completing treatment, it's important for us to monitor for many of the long-term effects, as well as for recurrent disease. Getting through those first five years is important as your risk for recurrent disease diminishes.

PEDIATRIC CANCER SURVIVORSHIP GUIDE

BECOMING A SURVIVOR

Part 4: The First Five Years

Featuring: Beatrix Currier, M.D. & Douard Dahgistani, M.D.



Miami Cancer Institute



(https://vimeo.com

/173640564)



Follow-up During the First 5 Years

Dr. Currier, "There are three goals for your follow-up care. First, to ensure that you are going in for your follow-up medical visits and getting the testing done to make sure that there's no recurrence of your disease. Second, we'll monitor and assess and treat any long-term effects or late effects that may have developed as a result of your cancer treatment. Third, we put a lot of emphasis on the education and promotion of wellness and educating you about preventive health behaviors to minimize your risk of developing any new cancers in the future."

Different cancers have different treatments. For instance, you may need to see your doctor on a monthly basis, or every 3 months. The simple way to make sure that your body is recovering from your treatment is to listen to your body. If there is any issue that your body is telling you, simply contact your doctor and they will inform you if it's something you need to worry about.



To Learn More:

- National Cancer Institute: Follow-up Care After Cancer Treatment (<http://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.

To Learn More:

- National Cancer Institute: When Cancer Returns (<http://www.cancer.gov/publications/patient-education/when-cancer-returns.pdf>)

After Five Years

PEDIATRIC CANCER SURVIVORSHIP GUIDE

BECOMING A SURVIVOR

Part 5: After Five Years

Featuring: Douard Dahgistani, M.D.



Miami Cancer Institute



(https://vimeo.com

Remaining Vigilant for Symptoms of Recurrence

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.

Long-term Survivorship

Dr. Dahgistani, "The first thing I want to tell you is congratulations! You survived your cancer, and you're a long term survivor. A long term survivor is a person who is alive without signs of cancer coming back five years or more after stopping treatment. The chances of recurrence

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of the same cancer after five years is very remote, and highly unlikely."

The goal of long term survivorship is to make sure you do not have any complications from your initial treatment, and if you do, treat it early.

What is Secondary Cancer?

Secondary cancer is a different type of cancer you get due to the treatment complications of your initial cancer. Depending on the type of treatment received and also depending on genetic predisposition, some people may be more at risk for secondary cancer.

To Learn More:

- Understanding Your Risk of Developing Secondary Cancer (https://www.nccn.org/patients/resources/life_after_cancer/understanding.aspx)
- Health Link: Reducing the Risk for Second Cancers (http://www.survivorshipguidelines.org/pdf/healthlinks/English/reducing_the_risk_of_second_cancers_Eng.pdf)

Participating in Research

If you are a long term survivor and you signed up for a clinical trial, you are already contributing to research. We follow you throughout your post-cancer journey. As long as you follow up with us and communicate with us about what's happening with your health, you are already participating in the research.



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 (<http://www.cancer.gov/types/aya>)
- Cancer Connects Volunteer Mentor Program (<http://www.cancerconnects.org/volunteerMentorProgram>)

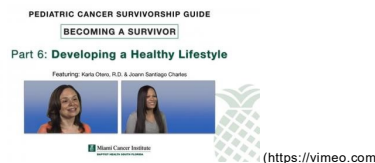
Developing a Healthy Lifestyle

Learning About a Healthy, Post-Cancer Diet

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Proteins

Protein is extremely important. Your body needs protein to heal, to build new tissues, to repair tissues, to build new blood cells and also to boost the immune system.

Good sources of protein include:

- Lean meats
- Poultry
- Fish
- Beans
- Peas
- Lentils
- Peanut butter

Carbohydrates

Carbohydrates are the preferred body's fuel for energy. Your cells need energy to maintain your organs so they can function well.

Good sources of carbohydrates include:

- Fruits and vegetables
- Grains (rice, pasta, bread, cereals)
- Potatoes
- Sweet potatoes
- Beans

Fats

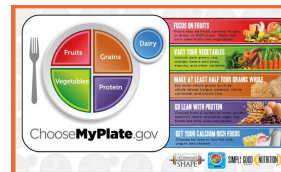
We need to focus on healthy fats. Fats are important because our body can store energy as fat, and also fat can help carry vitamins through the bloodstream.

Good sources of healthy fats include:

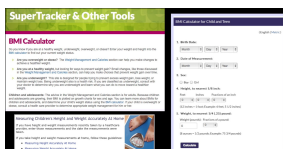
- Vegetable oil
- Avocados
- Nuts and seeds
- Fatty fishes like salmon

You can use **MyPlate** as a guide for a healthy, post-cancer diet. In this website, you'll find the 5 food groups as the building blocks of a healthy diet. It will help you learn how to eat healthy and plan your plate.

You want to fill half of your plate with fruits and vegetables. Fill one quarter of your plate with a lean protein and the other quarter of your plate should be filled with a grain (ideally a whole grain) so you can add the benefit of fiber. Lastly, include a serving of dairy in the form of fat-free/low-fat milk, yogurt, or cheese. These tips should help make a plate that looks colorful, healthy, and well-balanced.



www.ChooseMyPlate.gov (<https://www.choosemyplate.gov/>)



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. You want to make sure that your child maintains a healthy BMI.

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...

Not every calorie is created equal. You need to focus on the quality of the foods that you're eating. It is very important that you focus on fresh foods as opposed to processed foods. When it comes to cancer prevention, you need to know what foods to avoid.

Many of these foods have cancer causing chemicals that you want to stay away from.

Avoid foods high in added sugar such as:

- Sugary drinks
- Rich desserts

Avoid highly processed meats such as:

- Luncheon meats
- Sausages
- Salami
- Pepperoni
- Bacon

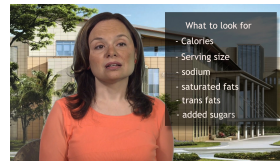
Avoid highly processed foods such as:

- Frozen meals
- Chicken nuggets
- Hot dogs

Your child can still enjoy these foods, but just not on a regular basis.

How to Read Food Labels

Label reading is extremely important because it tells you what the product is all about. What's in that product? What's your child eating? Learning how to read food labels can be tricky sometimes. It takes time. We need to take our time to start reading food labels, and teach our children how to read them as well.



What do you want to look at in a food label? You want to take a look at calories, serving size, ingredients such as sodium, saturated fats, trans fats, and added sugars.

Look at the ingredient list. The ingredients are listed in a descending order. Usually the first 3 are the ingredients with the largest amounts. Also, pay attention to the quality of the ingredients. Are they made from real foods, or are they mostly from chemicals that they have added to them? You want to go with the first one. You want the food to be as real as possible.

Use the labels to compare products and involve your child in this process. Pick your child's favorite cereal and select one you feel is better, and compare the ingredients together. This is a good teaching opportunity.

To Learn More:

- How to Understand and Use the Nutrition Facts Label

(<http://www.fda.gov/Food/IngredientsPackagingLabeling/LabelingNutrition/ucm274593.htm>)

- Read the food label (<https://www.choosemyplate.gov/budget-food-label>)

**Food Preparation**

Karla Otero, "We need to start cooking more! We live in a fast-paced society. We don't find time to cook, and homemade meals are invaluable. All the effort you put into healthy cooking is going to help provide your child with the right amount of nutrients. Offer your child new food choices. If you try new foods with them, they may be more willing to give it a try. Be a role model!"

Eat as a family. The family meal is a great opportunity to teach your child how to eat. Make it fun! Eating at home is healthy for your family in many ways.

As we learn more about the connection between certain diseases and lifestyle, we are more convinced that a healthy diet can actually decrease the risk for some of these health conditions, including cancer and cancer recurrence."

Start Moving and Setting Exercise Goals

Exercise plays a very important role in cancer rehabilitation specifically because it can prevent the recurrence of second cancers. It can also help to improve the patient's quality of life.

Exercise helps promote:

- Body image
- Muscle strength
- Muscle loss prevention
- Better sleep

● Focus

- Reduced blood pressure, cholesterol, and body weight

There are a lot of different aspects as to why exercise is beneficial.

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>)



Photography: CDC/Amanda Mills



Feelings of Sadness and Loneliness

While often after cancer treatment, patients undergo feelings of sadness, and exercise can help with that. When you engage in activity, your body releases certain chemicals that improve your mood and help you feel better. Exercise is one of the best anti-depressants you can engage in.

After the first year of treatment, the exercise goals are going to focus on finding your New Normal. If you had surgery and you need to improve range of motion, your exercise program should include some type of flexibility training. If you've lost muscle mass, you need to include some type of strength training component. There should always be some sort of cardiovascular component every day. Optimizing your New Normal should focus on a whole body approach.

Exercise is very important, but you also want to:

- Incorporate a healthy diet
- Drink plenty of water
- Make sure that you manage your emotional health and stress levels
- Get plenty of sleep at night

Joann Santiago Charles, "The goal is to exercise every day for at least 60 minutes. Ideally, if your child can't get to 60 minutes, they can start with whatever they can do. If they start with 10 to 15 minutes and then gradually increase over time, it's a better option than trying to force everything at one time. You can also spread out exercise over the course of the day, so they can do 10 minutes in the morning, 10 minutes in the afternoon, and 10 minutes in the evening, and then gradually build up their endurance. It shouldn't be forced, structured exercise, but more focused around play and making it fun and enjoyable for the child, so that they're willing to participate in it. For a child who just finished cancer treatment, I would say to stay positive, try a little bit each day, and don't be afraid to push and see what they can do. At first it may seem a little scary, but you'll be surprised what you can do if you try a little bit."



Photography: CDC/Amanda Mills

A Final Word

Dr. Daghistani, "Congratulations, you have been through a tornado and you survived! Together we need to look toward the future. You need to keep in contact with us, so we can help you develop a healthy lifestyle."

Mentoring is very helpful. Patients who get cancer, along with their families, go through shock, and sometimes depression. Sharing the experience you had with cancer will hopefully prove to be helpful to other future cancer patients."

PEDIATRIC CANCER SURVIVORSHIP GUIDE

BECOMING A SURVIVOR

Part 7: A Final Word

Featuring: Douard Daghistani, M.D.



Child Cancer Institute



(<https://vimeo.com>)

/175454187)

Long-term Survivorship



Part 3

Graduating From Pediatric Care

When is it Time to Graduate From Pediatric Care?

Mari Lourdes Garcia-Martinez, " *You will be graduating from the pediatric care team at 21 years of age. We will help you with a transition six months prior, and you will be meeting your adult specialist and getting to know them prior to your move.*"

To Learn More:

- Survivorship Guidelines (<https://childrensoncologygroup.org/index.php/survivorshipguidelines>)

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, numbers 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 lifetime 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 reports in a doctor's folder. This key key facts about your treatment will always be in the same place. Types of health information to include may be:

PEDIATRIC CANCER SURVIVORSHIP GUIDE

JOURNEY TO WELLBEING

Part 8: Graduating from Pediatric Care

Featuring: Mari Lourdes Garcia-Martinez, Oncology Social Worker



Miami Cancer Institute



(<https://vimeo.com>

/173710352)

The Importance of the Follow-up Plan

Your follow-up appointments and check-ups are extremely important. There may have been areas of concern that you need to follow up with a physician to see in the five years after your treatment, that those areas of concern are well taken care of.

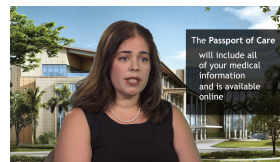
To Learn More:

- 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 (PCP)

If you stay here locally, your oncologist will be your primary care physician. If you move to another city or town, we will connect that oncologist with your oncologist here. We have something called the **Passport of Care**. We will hold all of your medical information and your new oncologist will be able to view your medical information, and you will have access to it. It's online, it provides you with your treatments, areas of concern that you had during your treatments, any follow-up appointments that you might need, and a future plan for the next five years.



Managing Stress, Fatigue, and School

Is It Normal to be Stressed After Cancer Treatment?

Once you transition out of active treatment, you may feel more anxiety because you don't have the constant medical contact with your healthcare team. You may feel vulnerable, you may not know what to expect, so this is a very important time to surround yourself with a support system to help you deal with that.

PEDIATRIC CANCER SURVIVORSHIP GUIDE

JOURNEY TO WELLBEING

Part 9: Managing Stress, Fatigue and School

Featuring: Beatriz Curtes M.D. & Mari Lourdes Garcia-Martinez, Oncology Social Worker



Miami Cancer Institute



(<https://vimeo.com>

/173713584)



Managing Stress After Cancer Treatment

Dr. Currier, "There are many things you can do to reduce your stress during this time: staying socially connected, staying physically active, eating well, and connecting with friends and family are all things you can actively do."

To Learn More:

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

Low Energy After Treatment

Cancer related fatigue is one of the most commonly reported side effects among cancer survivors. Moderate physical activity on a daily basis is the best treatment approach to help reduce that side effect and to help the patient restore their energy levels. The cancer related fatigue can vary among different patients, in some it may last weeks to months, and in others it may last up to two years.

To Learn More:

- General Info About Cancer Treatment & Fatigue (<http://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq#section/all>)



Going Back to School

Mari Lourdes Garcia-Martinez, "There's going to be some challenges. Remember, you have been in treatment for a number of years. Your life has been all about going to treatment, receiving your medicine, being healthy, and taking care of yourself. Now you are going to be going back to school in a whole different environment, but we will help you every step of the way. You have our psychological team and the social work team that will help you find ways to fit back into school."

To Learn More:

- Learning Problems after Treatment (<https://childrensoncologygroup.org/index.php/school-support-240/learning-problems-after-treatment>)

Teen and Young Adult Issues

What is Meant by 'Health Literacy'?

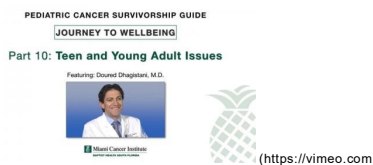
Health literacy is the understanding of the treatment you received, the terms associated with your cancer or disease, and the steps you need to take for your future wellbeing.

Finding Reputable Resources on the Web

There is a lot of information on the internet. The best way to judge that information is to take it to your doctor and ask their opinion on it.

A Few Suggested Sites:

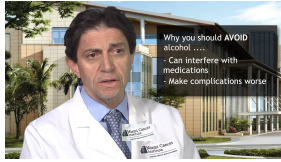
- National Cancer Institute (<http://www.cancer.gov/>)
- Children's Oncology Group (<http://www.childrensoncologygroup.org/>)
- American Cancer Society (<http://www.cancer.org/>)



/173809465)

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 (<http://www.cancer.gov/about-cancer/managing-care/using-trusted-resources>)

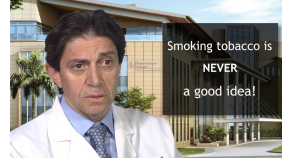


Alcohol and its Impact on Recovery

Drinking alcohol has its own problems. 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.

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.

Electronic cigarettes have nicotine. Nicotine is a chemical, and nicotine has a bad short-term and long-term complication on the body.

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 our knowledge of your medical condition. Using someone else's medication not only can be dangerous, it can be fatal. There is something called drug interaction, chemicals working against each other and causing more problems in the body. It's not advisable to take drugs without the advice of your doctor.

Working Towards Independence

Taking Leadership in Your Own Care

Mari Lourdes Garcia-Martinez, "Your relationship with your parents/guardians is going to change as you get older. Now you are going to be taking care of more of your medical needs. You're going to be making your appointments. You're going to be following your treatment. You're going to be taking more responsibility for what your medical decisions are. You are growing up. You are going to be able to say yes or no to different things, and that's very important in this transition. It's going to be hard with your parents/guardians at times, but you will make that transition safely, and we will help you with it."

We will be here to help you with your medical needs when you go away for college. We will provide you with your medical records and any resources you might need. We're always here to help you whenever you might have a question. You might hear the phrase "break up with your doctor." You don't break up with your doctor. Your oncologist will always want to know what's going on with your life."



PEDIATRIC CANCER SURVIVORSHIP GUIDE
JOURNEY TO WELLBEING
Part 11: Working Towards Independence
Featuring: Mari Lourdes Garcia-Martinez, Oncology Social Worker

MCI Cancer Institute
(https://vimeo.com/173713914)

To Learn More:

- Young Adults Transitioning to Adult Focused Care (<https://childrensoncologygroup.org/index.php/after-treatment-for-acute-lymphoblastic-leukemia-all/219>)
- For Caregivers: When Someone You Love Has Completed Cancer Treatment (<http://www.cancer.gov/publications/patient-education/someone-you-love-completed-cancer-treatment.pdf>)

Staying in Touch

Your oncologist and your pediatric team will always want to hear from you. We've been with you for so many years. We've seen you grow. We've seen you go through this treatment, and we want to know what's going on with you. Send us pictures, we want to see what you're doing, if you're travelling, where you're going to school, what are your successes. Whenever you can, stop by so we can


see your face.

From Healing to Wellbeing

Setting Long-Term Health Goals

It's very important for you to set long-term health goals. We need you to be as healthy as you can be. You need to exercise, eat healthy, stay away from any drugs or alcohol, because that can counteract any treatment that you received during your time with us.

PEDIATRIC CANCER SURVIVORSHIP GUIDE
JOURNEY TO WELLBEING
Part 12: From Healing to Wellbeing
Featuring: Mari Lourdes Garcia-Martinez, Oncology Social Worker & Oronod Daghistani, M.D.



Miami Cancer Institute
(https://vimeo.com/175126780)

To Learn More:

- Nutrition and Lifestyle in Cancer Survivors (<http://www.cancer.gov/about-cancer/treatment/side-effects/appetite-loss/nutrition-pdq#section/all>)
- Getting a Wellness Plan (<http://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>)

An Active Lifestyle Means a Healthy Lifestyle

It is extremely important for you to have an active lifestyle. By exercising, eating right, sleeping and taking care of yourself, this will help you fulfill your long-term goals.



Photography: CDC/Amanda Mills

To Learn More:

- Staying Healthy Through Diet and Physical Activity (<http://www.survivorshipguidelines.org/pdf/DietandPhysicalactivity.pdf>)
- Guidelines for a Healthy Lifestyle (<http://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>)
- Being Healthy After Treatment Ends (<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/behealthyaftertreatment/index>)
- Facing Forward: Life After Cancer Treatment (<http://www.cancer.gov/publications/patient-education/life-after-treatment.pdf>)


Get Busy Living... You're Past the Five Year Mark

Mari Lourdes Garcia-Martinez, *"What we mean by get busy living is exactly that, it's live your life. Live all the dreams that you wanted to do before cancer. You are such a strong individual, and now it's time to look forward to a beautiful, bright future."*

Dr. Daghistani, *"Follow your heart's desire. If you like to travel, travel. If you'd like more education, go back to school. Become the strongest survivor you can."*

You're a Survivor

PEDIATRIC CANCER SURVIVORSHIP GUIDE
JOURNEY TO WELLBEING
Part 13: You're a Survivor!
Featuring: Mari Lourdes Garcia-Martinez, Beatrix Currier, M.D., Niveth Matha, M.D. & Oronod Daghistani, M.D.



Miami Cancer Institute
(https://vimeo.com/173720320)

Video Compilation

This video is a compilation of all the videos in this Learn Guide. They contain information designed to help you through the entire patient journey, from diagnosis to wellbeing. **We suggest that you bring your ebook of this guide to meetings with Healthcare Professionals.** You can get the ebook from the "[Request Ebook of this Guide](#)" button above and will then be able to use it on your phone, tablet, computer, or print it out on paper.

PEDIATRIC CANCER SURVIVORSHIP GUIDE

AFTER TREATMENT

Part 1: **Congratulations!**

Featuring: Beatrix Currier, M.D. & Joana Santiago Charles



Memorial Sloan Kettering



(<https://vimeo.com/201500804>)

