SMART ALACC
Adult Living After Childhood Cancer

Nombre: ____________________

MR#: ____________________

Your Summary

Your personalized Smart ALACC Care Plan gives you information about the health risks you may face as a result of cancer therapies. Your level of risk can vary based on the doses and duration of your treatment and the combination of treatments received.

You should discuss this plan with your oncology team to better understand your personal risks. These results can be concerning, but not every survivor experiences every side effect, and some survivors do not experience any long-term effects. Learning about these risks can help you develop a plan with your healthcare provider to monitor for or reduce your risk for these side effects through screening and a healthy lifestyle.

The information in your plan is broken down by:

- Cancer therapies you received and related risks
- Future screening recommendations
- Healthy living tips
- Psychosocial issues you may face

You may see a particular side effect in more than one section because more than one therapy can cause the same long-term effect.

The information in this plan is based on the available research and literature concerning cancer survivors. This area is continually growing, and as new information becomes available, it will be added to the program. You may want to redo your plan periodically.

You received the following treatments for Neuroblastoma

- Removal of Abdominal Tumor
- Cyclophosphamide (Cytoxan®, Neosar®)
- Topotecan (Hycamtin®)
- Abdominal Radiation
- Radiografía basada - IMRT [X-ray based radiation- IMRT]

Information from your oncology office

Coordinating Your Care

As a survivor, it is important that you keep a treatment summary and a copy of your care plan. You may also include your doctor's information and current medications (Visit the OncoPilot section for forms you can use to organize this material). While some survivors continue to see an oncologist or specialized survivorship doctor, many return to a primary care provider or internist for routine care, many of whom are uncertain how to care for you. Developing the Care Plan can help you and your medical team understand what issues to look for, and how to handle them.

If you would like to find a long-term follow up clinic check out our list of clinics here (though this list is not exhaustive). A survivorship clinic will review the therapies you received, discuss your risks with you, and act as a consultant to your primary care team.

Qué hay en su plan de cuidado

Follow Up Care for Neuroblastoma

After completing treatment, you will have medical exams and imaging (which may include chest x-rays, CT scans, MRI scans or other studies) to monitor for your cancer coming back. In general, these exams and/or tests (including urine catecholamines) occur frequently (example: every 3 months) right after the end of therapy and are spaced out (to exery 6 months, and then yearly) over time. In general, the further from treatment, the lower the risk of recurrence, which is why medical studies like radiology studies are spaced out (and then not needed at all!) over time. Survivors and their healthcare team should begin to discuss keeping staying healthy in the long-term ("survivorship care"). Survivorship care includes all of the items discussed in this plan and may involve seeing other healthcare teams (like doctors or nurses who follow cancer survivors, primary care teams, or specialists) in additional to your primary oncologist and team.

Risks Related to Surgery

Removal of Abdominal Tumor

After surgery to remove a tumor, healing should be monitored in the short-term. In long term follow up, surgeries in the abdomen can infrequently cause abdominal issues such as pain or blockages. Let your physician know about any concerns.

🔑 Puntos Clave

- Report any abdominal pain or chronic constipation.

Risks Related to Medications

Risk of Bladder or Urinary Tract Toxicities

The risk for bladder and urinary tract toxicities is highest for survivors who received cyclophosphamide (at doses > 8g/m2), ifosfamide and/or radiation to the abdomen or pelvis. Late effects to the urinary tract can include hemorrhagic cystitis, a condition characterized by bleeding from the bladder lining and bladder scarring leading to a decrease in the bladder capacity. Symptoms of hemorrhagic cystitis include urinary frequency and urgency, blood in the urine and pain. Bladder scarring can present as difficulty urinating, frequency or urgency. There is also a risk of bladder cancer that can develop after treatment with cyclophosphamide, ifosfamide, or radiation to the abdomen or pelvis. Survivors at risk should report these urinary symptoms to their healthcare provider right away. Survivors should understand that alcohol use and smoking can contribute to bladder dysfunction, so these should be avoided.

🔑 Puntos Clave

- Avoid alcohol and smoking.
- Report the following symptoms to your healthcare provider:
  - Pain when urinating
  - Urinary hesitancy (difficulty starting the stream)
  - Urinary urgency or frequency
  - Getting up in the middle of the night to urinate
  - Blood in your urine

Risk of Developing Bladder Cancer

Cyclophosphamide can contribute to the development of bladder cancer. This risk is increased for those who also received radiation therapy to the abdomen or pelvis. Symptoms of bladder cancer include blood in the urine, urinary frequency and urgency, urinating at night and incontinence and should be reported to the healthcare provider. Survivors should be aware that alcohol use and smoking can contribute to bladder cancer, so these should be avoided.

🔑 Puntos Clave

- Avoid alcohol and smoking.
- Report the following symptoms to your healthcare provider:

  - Pain when urinating
  - Urinary hesitancy (difficulty starting the stream)
  - Urinary urgency or frequency
  - Getting up in the middle of the night to urinate
  - Blood in your urine

Skin Toxicities

Some cancer medicines can cause your skin or nails to darken all over, or in spots. The change in skin color tends to fade over time, but can become permanent. Many people will have very dry or scaly skin while on cancer treatments. Your nails may become weak and brittle. Taking care of your skin and nails can help them recover. Protect your skin from the sun with SPF, protective clothing and avoid the sun during peak hours (10am-3pm).

- Use a mild soap and water for washing.
- Use a hydrating cream or lotion for dry or scaly skin.
- Keep your nails trimmed to avoid them ripping. Do not use fake nails or gel manicures as these can further damage your nails.
- Protect your skin from the sun.

Puntos Clave

- Care for your skin with mild soaps and hydrating lotions.
- Protect your skin from sun damage.

Learning Differences

Many survivors who have previously received or are currently undergoing chemotherapy report experiencing cognitive changes. These changes include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration ability. Medications that may cause learning differences include intrathecal methotrexate and any radiation to the brain. Studies have found that cognitive ability can improve over time in some survivors, but deficits are still present in many long-term survivors, years after treatment.

It is important to remember that some very treatable problems can result in cognitive difficulties, such as thyroid dysfunction, depression and anxiety, so it is important to check for these problems and treat them, if present. Hypothyroidism (low thyroid hormone levels) is a common issue for survivors and can make you feel "fuzzy" or "out of it." This is easily treatable with supplemental thyroid hormone medication. Survivors who may be depressed or are experiencing anxiety would benefit from consulting with a psychiatrist or psychologist experienced in working with cancer patients or survivors.

Some medications are being studied as potential treatments for cognitive changes, but there is not yet enough data to support their use. Some of the agents being studied include: methylphenidate (Ritalin), modafinil (a medication approved to treat narcolepsy), various antidepressants, herbal therapies, such as ginkgo biloba, ginseng and certain amino acids. Neurocognitive testing and cognitive rehabilitation may be of use to survivors. Cognitive rehabilitation programs are structured programs utilizing exercise, tasks that use memory and puzzles to "rehabilitate" one's mind. These programs are typically used for people with brain injuries, but therapists have tailored programs for cancer survivors. Bookstores and websites offer memory training, which may be helpful to survivors. Puzzles using numbers, like Sudoku, may help "exercise" your brain. Fatigue can enhance cognitive problems, so avoiding fatigue by getting enough sleep, incorporating exercise into your life, and eating a healthy diet may be helpful.

Puntos Clave

- Let your healthcare team know if you have trouble with short term memory, multi-tasking, new learning, reading comprehension, working with numbers or a decrease in concentration ability that is affecting your day to day life.

Fertility and Sexuality Concerns for Male Survivors

Fertility (or the ability to have children) after cancer therapy is a very complex topic. It is related to the doses and types of medications received, if radiation or surgery to reproductive organs was performed and the age at time of treatment. With all of these variables, it is sometimes difficult to predict a survivor's reproductive health.

Survivors who wish to father a child or assess their fertility should consider seeing a reproductive specialist who has experience working with cancer survivors. There is testing a specialist can perform to help evaluate fertility, including certain hormone levels and sperm counts.

Chemotherapy agents that are most strongly tied to infertility include: alkylating agents (like cyclophosphamide and ifosfamide), and risks are higher with higher doses of these medications. Radiation fields that include the testes, brain or full body (TBI) can also affect fertility. It is not well understood how many of the newer agents will affect long term fertility.

There may be other concerns about sexual health for male survivors as well (like low testosterone levels, low sexual desire, or erectile dysfunction). An important first step is acknowledging the problem and seeking the help of a urologist who specializes in these issues.

All men should use protection if sexually active while assessing fertility and to protect against sexual transmitted infections.

Puntos Clave

- Survivors wishing to father a child can obtain a semen analysis via their health care provider to assess their current fertility.
- Survivors dealing with other sexual concerns should seek the help of an urologist.

Risk of Developing a Secondary Cancer

A secondary cancer is one that develops as a result of cancer treatment for another cancer. This is quite rare, but you should be aware of the risk.

Certain chemotherapy medications can cause damage to the blood cells in the bone marrow. In rare cases, this damage can cause leukemia or myelodysplasia (MDS) to develop years after therapy has been completed. Both diseases cause an abnormal production of poorly functioning blood cells, making it difficult for the body to fight infection, carry oxygen to the tissues and prevent bleeding. Because these conditions develop as a result of chemotherapy or radiation exposure, they are often more difficult to treat than typical leukemia or MDS. Leukemia and MDS caused by chemotherapy or radiation therapy typically occurs between 4-10 years after treatment, but can occur even later. One exception is those caused by etoposide

(VP-16) or teniposide (two types of chemotherapy), which generally occur within 1-3 years after therapy. Secondary lymphomas have also been seen in Hodgkin's disease survivors who received the MOPP (nitrogen mustard, vincristine, procarbazine, and prednisone) chemotherapy regimen. The medication bendamustine has been linked to secondary lung cancers.

Puntos Clave

- There is a small risk of developing leukemia, myelodysplastic syndrome, lymphoma or other cancer years after your treatment is completed.
- The risk is higher in the first 10 years after your treatment.
- Report the following symptoms to your healthcare provider promptly:
  - feeling more tired or weaker than usual
  - looking pale
  - shortness of breath
  - loss of appetite
  - weight loss
  - chills, fevers, night sweats
  - painless swelling of a lymph node
  - easy bruising, nose bleeds, or bleeding from the gums
  - pain in your bones
- Consider having a complete blood count with differential checked by your healthcare provider if you experience any of the above symptoms.

Side Effects of Radiation

Long term effects of radiation therapy vary greatly depending on the areas included in the field of radiation and the radiation techniques that were used, as these continue to develop and improve. One issue that is consistent across all tissues is the possibility of developing a second cancer in or near the radiation field. Secondary cancers develop as a result of the exposure of healthy tissue to radiation. Newer radiation techniques are designed to limit this exposure, but it is not always possible to prevent all exposure and still achieve the desired outcomes.

Abdominal Radiation

Radiation including the abdomen can affect several organs like the spleen, liver, kidneys and reproductive organs. If you were treated as a young child, we sometimes consider abdominal radiation as affecting structures in the chest like heart, lungs or breasts – since children are smaller. This can be discussed with your cancer-follow up team.

Bladder Health

Radiation fields that include the bladder can lead to a few bladder health concerns. The bladder can develop scar tissue, which can lead to a decrease in how much urine your bladder can hold.

If given with chemotherapy medicines known to cause bladder damage (cyclophosphamide, ifosfamide), late effects can include hemorrhagic cystitis (bleeding from the bladder lining). Symptoms of hemorrhagic cystitis include urinary frequency (needing to go often) and urgency (needing to go quickly), blood in the urine and pain. You should report these symptoms to your provider right away.

Radiation to the bladder can damage nerves that control bladder function. This is called neurogenic bladder and can cause the bladder to not empty completely or need to be emptied too frequently. It can also make you more susceptible to urinary tract infections. Any symptoms of urinary burning, frequency, needing to wake up at night often to urinate, having incontinence of urine, fever, pain with urinating or blood in the urine should be reported right away to your provider.

Radiation to the bladder can increase the risk of developing bladder cancer. Symptoms may include blood in the urine, urinary frequency and urgency, urinating at night and incontinence. Contact your care provider if you have any of these symptoms.

You may have noticed that late effects on the bladder all have similar symptoms. You may have urine tests or cystoscopy (inserting a small tube with a camera into the bladder) to figure out what is causing your symptoms. It is best to avoid alcohol use and smoking, as these irritate the bladder and increase the risk of bladder cancer.

Puntos Clave

- You should report any new or worsening bladder symptoms to your provider.
- You should avoid alcohol use and smoking as these can further irritate the bladder.

Maintaining Healthy Skin

Radiation can lead to permanent changes in the skin. This can include changes in the color or texture of the skin or scars. There can also be changes in the color and texture of hair or permanent loss of the hair in the treated area. The soft tissue and muscles under the skin can develop scarring and/or shrinkage, which can cause the area to be less flexible, difficult to move or to have chronic swelling. Some patients develop chronic or recurring ulcers of the skin in the area treated. Blood vessels of the skin in this area may become more noticeable, although this is not harmful. If the skin feels tight or sore, regularly applying vitamin E to the skin can be helpful.

After radiation, the skin is more sensitive to sunlight, and you should be especially cautious to use sunscreens when outdoors.

Puntos Clave

- You should use sunscreen anytime you are outdoors.
- You should see a wound care specialist or surgeon if you have any skin wound or ulcer that does not heal.

Your Spleen After Radiation

The spleen is an organ located in your upper abdomen that functions somewhat like a filter, removing bacteria and dead red blood cells from the bloodstream. Radiation directly to the spleen often results in your spleen not working. Unless your care team has told you otherwise, you should assume that your spleen is not functional.

If you have a non-functioning spleen you are at higher risk for infections caused by certain types of bacteria, of which *Streptococcus pneumoniae* and *Haemophilus influenzae* type b are the most common. An infection can rapidly progress to sepsis and can lead to death if not treated quickly with antibiotics. Some experts believe survivors should have antibiotics on hand to be started at the first sign of infection, even before being seen by your healthcare provider. You must be aware of the importance of reporting a fever (temperature < 100.4° / 38° C) or any sign of infection to your healthcare provider right away or to go to an emergency room. Be sure any healthcare provider caring for you knows that you do not have a functioning spleen.

You should wear a medic-alert bracelet noting this condition ("asplenia"). You should receive annual influenza vaccines, as well as the pneumococcal, and Hepatitis B, meningococcal and *H. influenzae* type b vaccines (this is not the same as the annual flu vaccine). If you are bitten by a dog, cat or rodent, antibiotics are required to prevent infection with *Capnocytophaga canimorsus* bacteria.

If you are traveling to an area with malaria, taking medication to prevent infection with malaria and the use of a mosquito repellent are important. If you notice you have been bitten by a tick, please contact your healthcare provider as soon as possible as ticks may transmit Lyme disease. If traveling to or living in Cape Cod or Nantucket Island in Massachusetts, you may be more likely to have complications from an infection called Babesia, which is caused by deer ticks.

Puntos Clave

- You should wear a medic alert bracelet stating that you have “asplenia” (no functioning spleen). You can get one from the MedicAlert Foundation.
- Notify your healthcare team right away if you develop a temperature greater than 100.4° F / 38° C or any signs of infection (sore throat, cough, burning with urination, ear pain, rash or shortness of breath).
- You should receive an annual flu vaccine as well as pneumococcal, Haemophilus influenza type b (Hib), meningococcal and hepatitis vaccines (per CDC guidelines).
- When traveling outside the U.S., speak with your provider to see if you need other vaccines or antibiotics.
- See your provider for any tick or animal bites.

Liver Health

Radiation to the liver can lead to abnormal liver function or liver failure. Your provider will check your liver function before and after treatment with blood tests. You should have an annual exam by an oncologist or primary care provider to evaluate for signs of liver damage, and liver function testing should be done if you have any signs of liver disease. If you have any abnormalities, you may benefit from seeing a gastroenterologist. You should avoid alcohol use as this increases the risk of radiation-induced liver injury.

Puntos Clave

- Your provider will check your liver function before and after treatment with blood tests.
- You should have an annual exam by a healthcare provider to evaluate for liver disease.
- Do not drink alcohol, as it increases the risk of damage your liver.
- If you develop any symptoms of liver disease or abnormal testing results, you benefit from seeing a gastroenterologist.

Bowel Health

The bowel is very sensitive to radiation, and several late effects may occur after radiation to the rectum, colon, or small bowel:

Scar tissue and strictures (narrowing) can lead to bowel obstruction, which is most commonly seen in people who had surgery and/ or radiation to the abdomen. If you have any signs of bowel problems, they should be reported to a healthcare provider. Things to report include abdominal pain, constipation, vomiting, weight loss and bloating. If you have severe abdominal pain accompanied by vomiting and constipation, you should be seen by a provider immediately, either in the office or the emergency department. If you develop a bowel obstruction, you should be followed by a gastroenterologist or surgeon after this.

Ulceration and bleeding of the bowel can occur after radiation. Bowel tissue is very delicate and can be damaged by radiation. If you have bright red blood in your stools, toilet water, or on toilet paper, or dark black stools, you should report this to a provider right away. These can be signs of radiation colitis or proctitis and may require evaluation with colonoscopy.

Chronic diarrhea or poor absorption of nutrients can result from radiation to the bowel. If you develop diarrhea with weight loss or malnutrition, you should be seen by a gastroenterologist. Anti-diarrheal or anti-spasmodic medicines may be helpful. It can be helpful for survivors who continue to lose weight or have electrolyte abnormalities to see a dietitian.

Fistula formation: A fistula is a connection between two body cavities that do not normally exist. A fistula can form between the bowel and bladder, bowel and female reproductive system (uterus/ vagina), or the bowel and the skin. A fistula between the bowel and bladder may cause a survivor to pass gas or stool through the urethra (the tube that drains urine). Any abnormal passage of urine, feces, or blood should be immediately reported to a healthcare provider and will likely need evaluation by a surgeon.

As is true when any part of the body receives radiation, research indicates that radiation to the bowel can lead to colon cancer. Survivors should have colonoscopy or DNA stool testing to screen for polyps or colon cancer. The Children's Oncology Group guidelines for childhood cancer survivors recommend that survivors who received abdominal radiation begin screening colonoscopy 10 years after radiation or at age 35 (whichever is later), with repeat colonoscopy every 5 years. For patients unable to undergo colonoscopy, and multitarget stool DNA test every 3 years is a reasonable alternative. Screening of the general population begins at age 50. Depending on your age during treatment, the amount of radiation you received, and your family and health history, you and your provider should discuss when is best for you to begin screening. Survivors who may require earlier screening include those with irritable bowel disease, chronic diarrhea or bleeding, ulcerative colitis, familial colon cancer syndromes or previous gastrointestinal cancers or polyps.

Puntos Clave

- You should seek immediate medical care for severe abdominal pain, especially if accompanied by nausea/ vomiting and constipation or for bleeding from the rectum or dark stools.
- Anti-diarrheal medicines can be helpful for chronic diarrhea.
- You should see a dietitian if you have unintended weight loss or nutritional deficits.
- Screening colonoscopy is recommended for all people beginning at age 50. For those who received abdominal radiation, screening colonoscopy is recommended beginning 10 years after radiation therapy (or at age 35, whichever is later), with repeat colonoscopy every 5 years.

Kidney Health

Radiation including the kidney can result in renal insufficiency (decreased kidney function) and hypertension (high blood pressure). This risk is higher in people with diabetes, those with only one kidney, people who already have high blood pressure, and used along with other treatments or medications known to cause kidney damage. You should have an annual physical by a healthcare provider. This should include checking your blood pressure and having blood work and urine testing to check kidney function. Survivors should have strict control of blood pressure with medications when necessary, and any survivor with diabetes should have strict control of blood sugar levels as these can both cause kidney damage.

Puntos Clave

- You should see your healthcare provider at least once a year for a physical, including screening for hypertension (high blood pressure) and diabetes mellitus.
- You should have blood work and urine testing to screen for kidney problems once a year.
- You should have good control of any high blood pressure or blood sugar as these can also damage the kidneys.
- If you develop kidney disease, you should be seen by a nephrologist.

Healthy Living After Cancer

Survivors often wonder what steps they can take to live healthier after cancer. There is no supplement or specific food you can eat to assure good health, but there are things you can do to live healthier, prevent other diseases, and detect any subsequent cancers early. In addition, cancer survivors can also have concerns related to insurance, employment, relationships, sexual functioning, fertility and emotional issues because of their treatment - these are addressed in the Life After Cancer tab. It is also important to have a plan for who will provide your cancer-focused follow up care (an oncologist, survivorship doctor, or primary care doctor).

A Note on Genetics

Many survivors have questions about the genetics of their cancer and what that means for them or their family members. It is common for families to have more than one person who is affected by cancer. Most of the time, this is a random occurrence, but there are some cancers that are known to be associated with specific genes (part of a person’s DNA), that can be passed from one family member to the next generation.

Healthcare providers will assess this risk by asking your personal and family history of cancer. If you have concerns that cancer “runs in your family” you should speak to your care team and they can help determine if there is a known risk for you. Information you should find out for your care team includes: types of cancer in your family, at what general age people had cancer, family members who have multiple cancers and whether other risk factors were involved (like smoking).

Note, very few cancers are known to have this type of risk (less than 10%). If healthcare providers have concerns, some patients will be referred to a genetic counselor for further testing.

Often, survivors of childhood cancer will have additional questions about the risk of cancer (or other problems like birth defects) for their children because of their history of cancer and cancer treatment. Luckily, looking at large groups of adult survivors there is no known increased risk of childhood cancer or birth defects in children of cancer survivors just because their parents had cancer.

Cancer Prevention and Screening After Cancer

In anyone who has been treated for one cancer, one goal of medical care should be to prevent other cancers or detect them early!

Are cancer survivors at increased risk of cancer?

Some studies have found that cancer survivors are more likely to develop another cancer when compared to someone who has never had cancer. In some cases, a treatment (certain types of chemotherapy or radiation therapy) can increase the risk of another cancer. These are called "secondary cancers" because they develop as a result of treatment. The increased risk of developing another cancer may also be related to exposure to risk factors (smoking, for example), or a genetic predisposition in certain individuals, but in many cases the reason for the increased risk is unclear. While this may sound scary, it is a reminder of the importance of cancer screening and maintaining a healthy lifestyle in your post-cancer life.

General Cancer Screening for Men after Neuroblastoma

Cancer screening tests are designed to find cancer or pre-cancerous areas before there are any symptoms and, generally, when treatments are most successful. Various organizations have developed guidelines for cancer screening with available tests. For many cancers, healthy lifestyle behaviors may decrease the risk of cancer.

Cancer prevention and screening for the general public (and all survivors, unless they are told they need additional screening) includes:

- HPV Vaccine: Human Papilloma Virus (HPV) is a virus that causes cervical, anal, and penile cancers and certain cancers of the head and neck. Therefore, all who are eligible (boys and girls) should receive the HPV vaccine.
- Sun Protection: Skin cancer is one of the most common types of cancer. Practicing sun-safety, including not tanning outside or in tanning beds, and wearing sunscreen and protective clothing, can reduce your risk of skin cancer. Of note, those with darker skin pigment are still at risk of getting skin cancer. People who have received radiation are at higher risk.
- Colon Cancer: Most men and women over the age of 50 should undergo routine screening for colon and rectal cancer. This may be done with colonoscopy (most common) or other imaging or stool tests. Testing may be appropriate for younger people with a high-risk personal or family health history. In particular, the Children’s Oncology Group recommends that all young people who have required radiation to the abdomen, pelvis, lower spine, or total body undergo colorectal cancer screening every 5 years, beginning either 5 years after radiation or at age 30, whichever is LATER. Colonoscopy is the best test for colorectal cancer, although other potential tests are mentioned in the radiation risk section of the care plan.
- Healthy Living: A healthy diet and physical activity are helpful for a number of health conditions, including cancer prevention. Avoid drinking alcohol. If you choose to drink, try to limit to 1 drink per day and do not binge drink (drinking a lot of alcohol in a short period of time).
- Not smoking! Tobacco is addictive and linked to several types of cancer (not just lung cancer). All types of tobacco and cigarettes, including electronic cigarettes, should be avoided to prevent cancer.

Prostate Cancer Screening

There are two ways to screen for prostate cancer. The first is a blood test called a PSA (prostate specific antigen) and the other is a rectal exam to feel the prostate. Both have the benefit of detecting prostate cancer at an early stage, but the downside is that they have many false positives (the test coming back "positive" or worrisome for cancer when there is actually no cancer). For this reason, the American Cancer Society (ACS) recommends that men discuss the risks and benefits of prostate cancer screening with their healthcare provider, and make an informed decision about whether to be screened or not. Most men (those at average risk for prostate cancer) should have this discussion starting at age 50. Men with a father or brother who had prostate cancer before age 65, and all African American men, should have this talk starting at age 45.

Genetic Risk

Cancer is a condition where certain cells in the body are no longer growing and dividing normally. Genes are the instruction manuals contained in all of our cells. Cells receive many instructions from genes about when to grow and divide, and when to stop growing. If certain genes are not working properly (they have a mutation) then cells may not get the proper instructions about when to grow and divide and, as a result, cancer can develop.

In families with hereditary forms of cancer risk, a mutation is present in a single, very important gene, and is present at birth in all cells in the body. A child may inherit this gene mutation from a parent. Inheriting a mutation in a gene that plays a very important role in controlling normal cell growth substantially increases cancer risk. However, these cancer risk genes in no way guarantee that cancer will develop; inheriting a mutation in a cancer risk gene means only that your risk is higher than someone who does not carry such a mutation in their cells.

The American Society of Clinical Oncology suggests that you consider genetic testing if your personal or family history is suggestive of a genetic mutation, including:

- Cancer diagnosed at an unusually young age.
- Several types of cancer in the same person.
- Cancer in both organs in a set of paired organs, for example, both breasts or kidneys.
- Several close blood relatives with the same type of cancer (mother, sisters, daughter).
- Unusual cases of a specific cancer (for instance, breast cancer in a male).
- Presence of birth defects related to an inherited cancer syndrome (which can include skin growths or skeletal abnormalities).
- Being a member of a racial or ethnic group with a known higher risk of a hereditary cancer syndrome.

Not every family that has multiple cancer cases is found to have a genetic mutation. If you are concerned that your family may have such a mutation, you should consult with a genetic counselor. These trained professionals will review your detailed family history, discuss the risks, benefits, and limitations of genetic testing and help you decide what is right for you. If you do undergo genetic testing, the genetic counselor will help you understand how the results affect you and your family. They will also help you outline a plan for cancer screening that is tailored to your level of risk.

A Note on Fatigue

Some survivors report significant fatigue years after completing therapy, which can be extremely frustrating for the survivor and those around them. It is important to remember that fatigue can have many causes and, particularly if fatigue is worsening or new, it should be discussed with your healthcare team to rule out treatable causes.

While it may seem overwhelming to start exercising, many studies have shown that light to moderate exercise can combat fatigue and improve your energy level. Exercise can take many forms, from walking, gardening or swimming, to more structured classes at a gym. Start slow and gradually increase the amount and intensity of your activities. Enlist a friend to be an exercising partner, who can encourage and support you on days when you can't get motivated.

Puntos Clave

- After making sure that fatigue is not being caused by another problem, find ways to best cope and manage the fatigue. Regular exercise, acceptance, and reprioritizing will help.
- Alert your healthcare provider if fatigue is worsening or a new symptom.

Life After Cancer

Many survivors say they look at life differently: they don't take things for granted, and don't sweat the small stuff. A cancer diagnosis changes you as a person, something people around you may not fully understand. It may be helpful to join a group of survivors, either formally (in a support group) or informally (gather a few folks you have met along the way). Email and the Internet have created a wonderful support for all sorts of concerns, and survivorship is no different. CancerCare provides free counseling and support groups online and by phone. Stupid Cancer is an organization created for people under 40 that provides a community of survivors to connect with. No one understands this time better than someone who has been there, and this support can be very valuable.

After being diagnosed with cancer as a child or young adult, you may face challenges when returning to school or work or trying to reconnect with friends and peers. How you meet these challenges is unique to each survivor. For some, recovery from the trauma of cancer and its treatment can be made more difficult by complications of past treatment, which can affect quality of life. When emotions become too overwhelming, it may be helpful to seek a referral to a mental health professional. Signs of persistent depression and anxiety can include difficulty with sleep and daytime function, hopelessness, and thoughts of self-harm. These are indicators that professional help is needed. Ask your healthcare provider to recommend a psychological professional. Oncology social workers can also provide resources and referrals for ongoing mental health counseling. You can also search the Psychology Today’s Therapist Finder to learn more about practitioners in your geographic area.

If you are a student, your school may offer counseling and psychological services. These are usually offered as part of your tuition and fees. These counselors can be extremely helpful in navigating mental health issues in the context of pursuing your educational goals.

If you are working, you may want to start with your health insurance network of mental health providers or your employer’s Employee Assistance Program (EAP). Mental health services are required as an essential health benefit under the Affordable Care Act for most insurance plans. Contact your plan for a list of in-network providers.

Text based or online counseling is also an option. Talkspace is a text based platform that offers various types of virtual counseling and therapy. This can be a great choice if you live in an area where therapists may not be readily available.

Organizations for Support & Resources

The following websites and organizations offer support services and opportunities for survivors across the country, but make sure to look or ask your care team about for groups local to you as well!

American Association for Cancer Research (AACR)
http://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy
615 Chestnut St. 17th Floor, Philadelphia, PA 19106
The Survivor and Patient Advocacy Program creates partnerships among cancer survivors, patient advocates, and scientific communities. Membership applications are available for cancer survivors who

wish to become survivor advocates.

American Cancer Society: Cancer Survivors Network (CSN)
csn.cancer.org
Provides a community of cancer survivors and families through online chats and message boards, the Cancer Survivors Network, and support groups.

American Cancer Society: National Cancer Information Center
1-800-227-2345; https://www.cancer.org/about-us/what-we-do/providing-support.html
Not sure where to find what you need? American Cancer Society’s Cancer Information Services connects patients and families with all kinds of resources 24 hours a day, 7 days a week.

American Childhood Cancer Organization
www.acco.org
1-800-366-CCCF
The American Childhood Cancer Organization provides information, support and advocacy information. This is a self-help network for parents of children with cancer. Services include support from other families, reading materials, a quarterly newsletter for parents and professionals, and a newsletter for children.

Bite Me Cancer
www.bitemecancer.org
Bite Me Cancer is an organization that was started by a 19-year old with thyroid cancer. The group distributes teen support bags to hospitals around the country.

BMT InfoNet’s Caring Connections Program
www.bmtinfonet.org/services/support
This program matches bone marrow transplant patients and caregivers with survivors and experienced caregivers. Sign up online.

Camp Make-A-Dream Young Adult Survivors Conference (YASC)
www.campdream.org
406-549-5987
YASC is a six-day, cost-free, medically supervised educational program in Montana designed to address issues of survivorship, provide information about being a cancer survivor, and develop lasting supportive relationships between young adult survivors. They also offer conferences and camps that target specific groups, including teens, parents and families.

Cancer.net
www.cancer.net/patient/Survivorship
Cancer.net has survivorship resources, steps to take after cancer, information about late effects, and rehabilitation.

Children’s Oncology Group
www.survivorshipguidelines.org
The Children’s Oncology Group provides guidelines and recommendations about long-term follow-up for cancer survivors. There is information available about different diagnoses, possible side effects from treatment, co-occurring conditions, finances, late effects, and emotional issues.

Stupid Cancer

www.stupidcancer.org

Stupid Cancer is a national cancer advocacy, research, and support organization. They work to create shared experiences through live events and digital content that end isolation, build community, provide education, and foster meaningful relationships that last a lifetime. They also hold a large annual conference called CancerCon for Young Adults.

Schooling, Employment & Insurance

There are many resources to help survivors, but it can take some homework to find what you need. In dealing with schooling and employment issues, you should learn about your rights and your school/employer's responsibilities under the law.

If you are attending college, it is important to register with the Office of Disabilities at your school in case any issues related to your cancer therapy arise or for help with management of chronic health conditions while in school. Additional financial aid may also be available for students impacted by cancer.

OncoLink's section on insurance, legal, employment and financial concerns may be helpful. LIVESTRONG Navigation Services (online or 1-855-220-7777) is a free resource that can help you find resources and address financial, employment, insurance and coping concerns. The National Coalition for Cancer Survivorship and the American Cancer Society websites have financial and insurance information for survivors. The Cancer Legal Resource Center provides information on cancer-related legal issues, including insurance coverage, employment and time off, and healthcare and government benefits. Cancer and Careers is a resource for all things employment-related, from time of diagnosis well into survivorship.

Other resources that might be useful include:

- Health Insurance Web Portal (healthcare.gov)
- Pennsylvania Health Law Project (www.phlp.org)
- American Cancer Society (www.cancer.org)
- Livestrong (livestrong.org)
- Kaiser Family Foundation (kff.org)
- OncoLink Insurance Education Webinars

Fertility, Sexuality & Relationships

Personal issues related to sexuality or fertility can be emotionally draining, and can interfere with personal relationships at a time when you need them most. OncoLink's section on fertility & sexuality may be helpful. Organizations such as the Oncofertility Consortium and Resolve can help with fertility issues. The American Cancer Society provides fertility and sexuality resources. Your oncology team can recommend local counseling services if needed. CancerCare offers free counseling services by phone and online.

Dealing with a Recurrence or Second Cancer

When the fear of cancer coming back becomes reality, it can bring up many questions and emotions. This may be occur as a recurrence of the first cancer or a new cancer altogether. Can this be treated or cured? Am I up for another battle with cancer? Can my family handle it? Was my treatment a waste of time? What do I do now? You may feel fearful, shocked, angry, overwhelmed and out of control. Turn to those who gave you support during your first battle with cancer. Don't hesitate to seek out help and support- social workers, therapists, support groups (in person and online). Family, friends and clergy can be great sources of support during a second cancer battle. But keep in mind, you have done this before- you know much more now than you did at the time of your original diagnosis. Use that knowledge to guide your treatment decisions and help you put into place the support you need to get through this battle.

A recurrence or second cancer can mean different things to different people- each situation is unique. You may want to start aggressive treatment right away. Perhaps you just aren't sure you want to go through more chemotherapy or surgery. There is no "right" way to respond. Just as the initial treatment decisions are a balance of pros and cons, so are these decisions.

Ask your treating physician to describe all of your options and what treatment he or she recommends and why? How does your previous treatment affect this treatment? With the help of your support people, weigh the pros and cons of your treatment options. Consider your goals and how each treatment will impact them and your quality of life. You may want to consider seeing another physician to get a second opinion. Getting a second opinion does not mean you have to switch doctors; you are just getting input from another perspective. You may also want to research what clinical trials are available to you.

While surgery, chemotherapy or a clinical trial of a new medication may be the best option for some, others may feel that they don't want to pursue aggressive treatments again. And that is okay. It may not be a decision family and friends will understand, but it is the patient's decision to make. Talk with your team about palliative care and hospice options.

Some good resources:

- NCI publication, When Cancer Returns
- ACS resource, Coping With Cancer Recurrence

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