THE NCCS NEUROBLASTOMA SURVIVORSHIP HANDBOOK

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# The NCCS Neuroblastoma Survivorship Handbook

## Table of Contents

<table>
<thead>
<tr>
<th>Handbook Sections</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributors to the Handbook</td>
<td>3</td>
</tr>
<tr>
<td>The Neuroblastoma Children’s Cancer Society</td>
<td>4-6</td>
</tr>
<tr>
<td>General Information About Late Effects (From the NCI)</td>
<td>7-49</td>
</tr>
<tr>
<td>Second Cancers</td>
<td>9-12</td>
</tr>
<tr>
<td>Cardiovascular System</td>
<td>12-15</td>
</tr>
<tr>
<td>Central Nervous System</td>
<td>15-19</td>
</tr>
<tr>
<td>Digestive System</td>
<td>19-27</td>
</tr>
<tr>
<td>Endocrine System</td>
<td>27-34</td>
</tr>
<tr>
<td>Immune System</td>
<td>34-35</td>
</tr>
<tr>
<td>Musculoskeletal System</td>
<td>35-38</td>
</tr>
<tr>
<td>Reproductive System</td>
<td>38-41</td>
</tr>
<tr>
<td>Respiratory System</td>
<td>41-43</td>
</tr>
<tr>
<td>Senses</td>
<td>43-46</td>
</tr>
<tr>
<td>Urinary System</td>
<td>46-49</td>
</tr>
<tr>
<td>Fear of Recurrence/Relapse</td>
<td>50-52</td>
</tr>
<tr>
<td>Survivorship Resources and Information</td>
<td>53-57</td>
</tr>
<tr>
<td>Financial Assistance / Hearing Aid Support</td>
<td>58-62</td>
</tr>
<tr>
<td>College Scholarships</td>
<td>63-64</td>
</tr>
<tr>
<td>September Awareness and Advocacy</td>
<td>65-68</td>
</tr>
<tr>
<td>September - Childhood Cancer Awareness Month</td>
<td>65-67</td>
</tr>
<tr>
<td>Advocacy</td>
<td>67-68</td>
</tr>
</tbody>
</table>
CONTRIBUTORS
TO THE
HANDBOOK

Sarah McWhorter is the mother and primary caregiver to a neuroblastoma survivor. She brings her passion for pediatric cancer and mentoring heart to this NCCS handbook. Her son, Aiden, was diagnosed with Stage 4 High Risk Neuroblastoma in 2019 at the age of one. After the successful completion of the standard Children’s Oncology Group protocol for high risk neuroblastoma, Aiden relapsed in June of 2020. He is currently pursuing treatment at the Memorial Sloan Kettering Cancer Center and is now NED and looking forward to survivorship. When Sarah is not in treatment or enjoying travels of the world, she works as an ASL interpreter for the Deaf community in Indianapolis, IN.

Mariah Forster Olson was diagnosed with neuroblastoma in 1980 at the age of one, with a tumor growing out of her spine, wrapping around a portion of her heart, and occupying almost the entire right side of her chest. At that time, there were very few treatment options, and Mariah had them all – multiple surgeries, many radiation treatments, and two years of a new chemotherapy clinical trial, including cyclophosphamide, doxorubicin, and vincristine, which are still being used today! Outdated therapeutics and the location of her tumor have left Mariah with a number of complex medical conditions and late effects that greatly impact her life, but she strives to focus on hope, optimism, and positivity. Mariah is the Director of Survivor, Family, and Resource Services for NCCS, and she also serves on the NCCS Board and is the co-administrator of the “Neuroblastoma Family Support Group” on Facebook. Mariah also represents NCCS in the Coalition Against Childhood Cancer (CAC2), where she is the survivorship interest group liaison and the co-lead of the Leadership Transition Planning Team, and she also serves on the Board of Directors and on the Executive Committee. Mariah’s work truly fulfills her and gives her a sense of purpose, and she truly hopes to help others and provide hope, understanding, support, and encouragement. Mariah lives in La Crosse, Wisconsin with her husband, Troy, and their Siamese cat. In her spare time, Mariah volunteers for several additional nonprofit cancer organizations, is writing a book about her life, and plays the oboe professionally.
More than 15,000 children are diagnosed with one of the 16 different types of childhood cancer in the United States every year, making it the leading cause of death by disease among children. Neuroblastoma is one of the 16 types of childhood cancer that consists of a solid tumor that develops from nerve cells. It is the most common cancer diagnosed in infants, and 90% of neuroblastoma cases are diagnosed in children under five years old. Although neuroblastoma makes up 8% of all childhood cancer cases, it accounts for 15% of all childhood cancer-related deaths.

At the age of three, Michael Sexton courageously battled neuroblastoma for nine months, but his fight tragically ended in 1994. After Michael died, his parents, James and Dori Sexton, were shocked to learn that there were no major organizations funding significant research to promote a frontline treatment or a cure for neuroblastoma. In honor of Michael and other children who had died from neuroblastoma, the Neuroblastoma Children’s Cancer Society (NCCS) was formed and became a 501(c)(3) in 1994 in Hoffman Estates, Illinois.

The mission of the Neuroblastoma Children’s Cancer Society is to cure neuroblastoma and its related childhood cancers, as well as to improve the quality of life for patients, survivors, and their families. We accomplish this by raising funds to support researchers investigating the causes, treatments, and cures for neuroblastoma and related cancers. Other vital components to our mission are generating public awareness and providing support, resources, and assistance to the neuroblastoma community. Finally, we advocate for government research funding and associated public policies for all types of childhood cancers.

The Neuroblastoma Children’s Cancer Society is composed entirely of volunteers, and there are no paid staff or employees. Each person that volunteers for NCCS has been directly impacted by neuroblastoma, and we are patients, families and caregivers, survivors, and bereaved family members. Thus, each volunteer is highly invested in fulfilling the mission and goals of our organization. The Neuroblastoma Children’s Cancer Society gives the majority of our donations to research because childhood cancers are vastly and consistently underfunded, so it falls to private organizations to fill in the funding gaps to pay for this desperately needed research. We need better, less toxic treatments to treat all types of neuroblastoma and related childhood cancers, and to decrease the number and severity of late effects for neuroblastoma survivors. In addition, although the survival rates for high-risk
neuroblastoma have increased in the last few decades, we want to see this number continue to increase. There are also no standard treatments for relapsed neuroblastoma; rather each child receives individualized treatments and are often entered into clinical trials. Again, these clinical trials cost money, but this research is absolutely imperative if we are to treat and improve the survival rates of high-risk and relapsed neuroblastoma patients, who are primarily young children.

Between 1994, when NCCS originated, and 2020, we have donated more than $2 million to neuroblastoma research and we have formed partnerships with various hospitals, including the Children’s Hospital of Los Angeles and the Children’s Hospital of Philadelphia. The majority of our research funding, however, has been donated to the University of Chicago for various neuroblastoma research grants and projects. For example, NCCS has supported research grants for the Interactive International Neuroblastoma Information Network (IININ), the Neuroblastoma Virtual Tumor Bank, the International Neuroblastoma Risk Group (INRG) Classification System, New Approaches to Neuroblastoma Therapy (NANT) Clinical Trials, the Pediatric Cancer Data Commons (PCDC), and many others.

Various types of support and services are absolutely crucial for childhood cancer patients, families, and survivors, and we want them to know that NCCS is there for them in many different ways. For example, we offer a variety of resources and educational components because when a family is immersed in childhood cancer, they are incredibly overwhelmed because there is so much information to process in a short amount of time. Knowledge and education are very important when understanding what is happening with the diagnosis, treatment, and survival of neuroblastoma, so we want to make things a little easier by providing information all in one place. That way, they do not have to search for information on their own, and it is all housed in one area for families to refer to when needed. We also believe it is important to provide various types of support networks and assistance of neuroblastoma patients, families, and survivors, and we provide this through: our private Facebook group; our Facebook, Twitter, and Instagram pages; our website; and our membership in the Coalition Against Childhood Cancer. As more patients and families face neuroblastoma or a related childhood cancer diagnosis, and as others move toward survivorship, we want those in our community to be aware of NCCS so that we can help even more patients, survivors, and their families.

The list below contains a more complete picture of NCCS’ programs and services:

- Raising money and receiving donations for childhood cancer research are absolutely critical to the mission of NCCS, and aside from private gifts, we actively accomplish this through:
  - Annual fundraisers
  - Annual races
  - Facebook Birthday Fundraisers, Giving Tuesday, and other Facebook fundraisers
- “Neuroblastoma Family Support Group,” a private Facebook group for parents/caregivers, family members, patients, and survivors to share their stories, advice, questions, support, and anything else related to neuroblastoma. This page acts as a support group for members of our community, and it provides psychosocial support for patients, survivors, and their family members. ([https://www.facebook.com/groups/neuroblastomasupport/](https://www.facebook.com/groups/neuroblastomasupport/)). This group contains thousands of members, and also offers: a weekly discussion topic; a file containing neuroblastoma topics and corresponding resources information; and past posts categorized by topic, so that members can easily search by subject matter for relevant information and

- Social media accounts on Twitter (@Fight2CureKids) and Instagram (@neuroblastomacancer).
- Distributing toys, games, and crafting projects to various children’s hospitals throughout the year, including the “Have A Heart” program during Valentine’s Day.
- Membership in the Coalition Against Childhood Cancer (CAC2), which is an organization that “advances a variety of childhood cancer causes by unifying the childhood cancer community through broad-based coordinated action and collaboration that leverages the strengths and expertise of its individual members and minimizes duplication of effort.” One of our NCCS Directors and the Program Director for this grant is also on the Board of Directors for CAC2, and she leads their Survivorship Interest Group.

- Our Website (https://www.neuroblastomacancer.org/) – We received a grant for a grant program that began in November 2020 and ends in January 2022 to assist us in creating and launching our new website. The new website contains resources that were carried over and updated from our old website, as well as new, valuable resources and information for patients, families, and survivors of neuroblastoma. These include:
  - Two new NCCS Handbooks, one aimed at current neuroblastoma patients and one aimed at neuroblastoma survivors. The handbooks contain a wealth of information about neuroblastoma, ranging from diagnosis and treatment to survivorship and bereavement.
  - A forum for visitors to submit stories or questions.
  - Our Wall of Fame, featuring members of NCCS and their fight against neuroblastoma.
  - Various ways to advocate for childhood cancer legislation and funding.
  - A database of survivorship issues and accompanying information, research, and resources.
  - Link to the Hope Portal, which is a comprehensive database that provides patients, parents, and survivors with organizations from around the country that can provide assistance, as well as resources and information. This wealth of resources is courtesy of the Coalition Against Childhood Cancer.
  - Featured books and other resources about neuroblastoma.
  - A list of ways that members and volunteers can help NCCS in the fight against neuroblastoma and related childhood cancers.

REFERENCES


“Coalition Against Childhood Cancer: About Us.” Coalition Against Childhood Cancer, https://cac2.org/about-us
**All of the information in this section has been adapted from the National Cancer Institute, and it is available in its entirety at:** [https://www.cancer.gov/types/childhood-cancers/late-effects-pdq](https://www.cancer.gov/types/childhood-cancers/late-effects-pdq)

Late effects are health problems that occur months or years after treatment has ended.

The treatment of cancer may cause health problems for childhood cancer survivors months or years after successful treatment has ended. Cancer treatments may harm the body's organs, tissues, or bones and cause health problems later in life. These health problems are called late effects.

Treatments that may cause late effects include the following:

- Surgery.
- Chemotherapy.
- Radiation therapy.
- Stem cell transplant.

Doctors are studying the late effects caused by cancer treatment. They are working to improve cancer treatments and stop or lessen late effects. While most late effects are not life-threatening, they may cause serious problems that affect health and quality of life.

Late effects in childhood cancer survivors affect the body and mind.

Late effects in childhood cancer survivors may affect the following:

- Organs, tissues, and body function.
- Growth and development.
- Mood, feelings, and actions.
- Thinking, learning, and memory.
- Social and psychological adjustment.
- Risk of second cancers.
There are three important factors that affect the risk of late effects.

Many childhood cancer survivors will have late effects. The risk of late effects depends on factors related to the tumor, treatment, and patient. These include the following:

- **Tumor-related factors**
  - Type of cancer.
  - Where the tumor is in the body.
  - How the tumor affects the way tissues and organs work

- **Treatment-related factor**
  - Type of surgery.
  - Chemotherapy type, dose, and schedule.
  - Type of radiation therapy, part of the body treated, and dose.
  - Stem cell transplant.
  - Use of two or more types of treatment at the same time.
  - Blood product transfusion.
  - Chronic graft-versus-host disease.

- **Patient-related factors**
  - The child's sex
  - Health problems the child had before being diagnosed with cancer.
  - The child’s age and developmental stage when diagnosed and treated
  - Length of time since diagnosis and treatment.
  - Changes in hormone levels.
  - The ability of healthy tissue affected by cancer treatment to repair itself.
  - Certain changes in the child's genes.
  - Family history of cancer or other conditions.
  - Health habits.

The chance of having late effects increases over time.

New treatments for childhood cancer have decreased the number of deaths from the primary cancer. Because childhood cancer survivors are living longer, they are having more late effects after cancer treatment. Survivors may not live as long as people who did not have cancer. The most common causes of death in childhood cancer survivors are:

- The primary cancer comes back.
- A second (different) primary cancer forms.
- Heart and lung damage.

Studies of the causes of late effects have led to changes in treatment. This has improved the quality of life for cancer survivors and helps prevent illness and death from late effects.

Regular follow-up care is very important for survivors of childhood cancer.
Regular follow-up by health professionals who are trained to find and treat late effects is important for the long-term health of childhood cancer survivors. Follow-up care will be different for each person who has been treated for cancer. The type of care will depend on the type of cancer, the type of treatment, genetic factors, and the person's general health and health habits. Follow-up care includes checking for signs and symptoms of late effects and health education on how to prevent or lessen late effects.

It is important that childhood cancer survivors have an exam at least once a year. The exams should be done by a health professional who knows the survivor's risk for late effects and can recognize the early signs of late effects. Blood and imaging tests may also be done.

Long-term follow-up may improve the health and quality of life for cancer survivors. It also helps doctors study the late effects of cancer treatments so that safer therapies for newly diagnosed children may be developed.

**Good health habits are also important for survivors of childhood cancer.**

The quality of life for cancer survivors may be improved by behaviors that promote health and well-being. These include a healthy diet, exercise, and regular medical and dental checkups. These self-care behaviors are especially important for cancer survivors because of their risk of health problems related to treatment. Healthy behaviors may make late effects less severe and lower the risk of other diseases.

Avoiding behaviors that are damaging to health is also important. Smoking, excess alcohol use, illegal drug use, being exposed to sunlight, or not being physically active may worsen organ damage related to treatment and may increase the risk of second cancers.

**Secondary Cancers**

**Childhood cancer survivors have an increased risk of a second cancer later in life.**

A different primary cancer that occurs at least two months after cancer treatment ends is called a second cancer. A second cancer may occur months or years after treatment is completed. The type of second cancer that occurs depends in part on the original type of cancer and the cancer treatment. Benign tumors (not cancer) may also occur.

Second cancers that occur after cancer treatment include the following:

- Solid tumors.
- Myelodysplastic syndrome and acute myeloid leukemia.

Solid tumors that may appear more than 10 years after primary cancer diagnosis and treatment include the following:
Breast cancer. There is an increased risk of breast cancer after high-dose chest radiation treatment for Hodgkin lymphoma. Patients treated with radiation above the diaphragm that does not include lymph nodes in the armpit have a lower risk of breast cancer. The treatment of cancer that has spread to the chest or lung with chest radiation may also increase the risk of breast cancer. There is also an increased risk of breast cancer in patients who were treated with alkylating agents and anthracyclines but not with chest radiation. The risk is highest in sarcoma and leukemia survivors.

Thyroid cancer. Thyroid cancer may occur after neck radiation treatment for Hodgkin lymphoma, acute lymphocytic leukemia, or brain tumors; after radioactive iodine therapy for neuroblastoma; or after total-body irradiation (TBI) as part of a stem cell transplant.

Brain tumors. Brain tumors may occur after radiation treatment to the head and/or intrathecal chemotherapy using methotrexate for a primary brain tumor or for cancer that has spread to the brain or spinal cord, such as acute lymphocytic leukemia or non-Hodgkin lymphoma. When intrathecal chemotherapy using methotrexate and radiation treatment are given together, the risk of a brain tumor is even higher.

Bone and soft tissue tumors. There is an increased risk of bone and soft tissue tumors after radiation treatment for retinoblastoma, Ewing sarcoma, and other cancers of the bone. Chemotherapy with anthracyclines or alkylating agents also increases the risk of bone and soft tissue tumors.

Lung cancer. There is an increased risk of lung cancer after radiation treatment to the chest for Hodgkin lymphoma, especially in patients who smoke.

Stomach, liver, or colorectal cancer. Stomach, liver, or colorectal cancer may occur after radiation treatment to the abdomen or pelvis. The risk increases with higher doses of radiation. There is also an increased risk of colorectal polyps.

Treatment with chemotherapy alone or chemotherapy and radiation treatment combined also increases the risk of stomach, liver, or colorectal cancer.

Nonmelanoma skin cancer (basal cell carcinoma or squamous cell carcinoma). There is an increased risk of nonmelanoma skin cancer after radiation treatment; it usually appears in the area where radiation was given. Being exposed to UV radiation may increase this risk. Patients who develop nonmelanoma skin cancer after radiation treatment have an increased chance of developing other types of cancers in the future. The risk of basal cell carcinoma is also increased after treatment with chemotherapy drugs, called vinca alkaloids, such as vincristine and vinblastine.

Malignant melanoma. Malignant melanoma may occur after radiation or combination chemotherapy with alkylating agents and antimitotic drugs (such as vincristine and vinblastine). Survivors of Hodgkin lymphoma, hereditary retinoblastoma, soft tissue sarcoma, and gonadal tumors are more likely to be at a higher risk of having malignant melanoma. Malignant melanoma as a second cancer is less common than nonmelanoma skin cancer.

Oral cavity cancer. Oral cavity cancer may occur after stem cell transplant and a history of chronic graft-versus-host disease.

Kidney cancer. There is an increased risk of kidney cancer after treatment for neuroblastoma, radiation treatment to the middle of the back, or chemotherapy such as cisplatin or carboplatin.

Bladder cancer. Bladder cancer may occur after chemotherapy with cyclophosphamide.
Myelodysplastic syndrome and acute myeloid leukemia may appear less than 10 years after a primary cancer diagnosis of Hodgkin lymphoma, acute lymphoblastic leukemia, or sarcoma and treatment with chemotherapy that included the following:

- Alkylation agent such as cyclophosphamide, ifosfamide, mechlorethamine, melphalan, busulfan, carmustine, lomustine, chlorambucil, or dacarbazine.
- Topoisomerase II inhibitor agent such as etoposide or teniposide.

Certain genetic patterns or syndromes may increase the risk of a second cancer.

Some childhood cancer survivors may have an increased risk of developing a second cancer because they have a family history of cancer, an inherited cancer syndrome such as Li-Fraumeni syndrome, or a genetic mutation such as neurofibromatosis type 1. Problems with the way DNA is repaired in cells and the way anticancer drugs are used by the body may also affect the risk of second cancers.

Patients who have been treated for cancer need regular screening tests to check for a second cancer.

It is important for patients who have been treated for cancer to be checked for a second cancer before symptoms appear. This is called screening for a second cancer and may help find a second cancer at an early stage. When abnormal tissue or cancer is found early, it may be easier to treat. By the time symptoms appear, cancer may have begun to spread.

It is important to remember that your child's doctor does not necessarily think your child has cancer if he or she suggests a screening test. Screening tests are given when your child has no cancer symptoms. If a screening test result is abnormal, your child may need to have more tests done to find out if he or she has a second cancer. These are called diagnostic tests.

The kind of test used to screen for a second cancer depends in part on the kind of cancer treatment the patient had in the past.

All patients who have been treated for cancer should have a physical exam and medical history done once a year. A physical exam of the body is done to check general signs of health, including checking for signs of disease, such as lumps, changes in the skin, or anything else that seems unusual. A medical history is taken to learn about the patient’s health habits and past illnesses and treatments.

If the patient received radiation therapy, the following tests and procedures may be used to check for skin, breast, or colorectal cancer:

- **Skin exam**: A doctor or nurse checks the skin for bumps or spots that look abnormal in color, size, shape, or texture, especially in the area where radiation was given. It is suggested that a skin exam be done once a year to check for signs of skin cancer.
- **Breast self-exam**: An exam of the breast by the patient. The patient carefully feels the breasts and under the arms for lumps or anything else that seems unusual. It is suggested that women treated with a higher dose of radiation therapy to the chest do a monthly breast self-exam beginning...
at puberty until age 25 years. Women who were treated with a lower dose of radiation to the chest may not need to begin checking for breast cancer at puberty. Talk to your doctor about when you should begin breast self-exams.

- **Clinical breast exam (CBE):** An exam of the breast by a doctor or other health professional. The doctor will carefully feel the breasts and under the arms for lumps or anything else that seems unusual. It is suggested that women treated with a higher dose of radiation therapy to the chest have a clinical breast exam every year beginning at puberty until age 25 years. After age 25 years or 8 years after radiation treatments end (whichever is first), clinical breast exams are done every 6 months. Women who were treated with a lower dose of radiation to the chest may not need to begin checking for breast cancer at puberty. Talk to your doctor about when you should begin clinical breast exams.

- **Mammogram:** An x-ray of the breast. A mammogram may be done in women who had a higher dose of radiation to the chest and who do not have dense breasts. It is suggested that these women have a mammogram once a year starting 8 years after treatment or at age 25 years, whichever is later. Talk to your doctor about when you should begin to have mammograms to check for breast cancer.

- **Breast MRI (magnetic resonance imaging):** A procedure that uses a magnet, radio waves, and a computer to make a series of detailed pictures of the breast. This procedure is also called nuclear magnetic resonance imaging (NMRI). An MRI may be done in women who had a higher dose of radiation to the chest and who have dense breasts. It is suggested that these women have an MRI once a year starting 8 years after treatment or at age 25 years, whichever is later. If you had radiation to the chest, talk to your doctor about whether you need an MRI of the breast to check for breast cancer.

- **Colonoscopy:** A procedure to look inside the rectum and colon for polyps, abnormal areas, or cancer. A colonoscope is inserted through the rectum into the colon. A colonoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove polyps or tissue samples, which are checked under a microscope for signs of cancer. It is suggested that childhood cancer survivors who had a higher dose of radiation to the abdomen, pelvis, or spine have a colonoscopy every 5 years. This begins at age 35 years or 10 years after treatment ended, whichever is later. If you had radiation to the abdomen, pelvis, or spine, talk to your doctor about when you should begin to have a colonoscopy to check for colorectal cancer.

### Cardiovascular System

**Heart and blood vessel late effects are more likely to occur after treatment for certain childhood cancers.**

Treatment for these and other childhood cancers may cause heart and blood vessel late effects:

- Acute lymphoblastic leukemia (ALL).
- Acute myelogenous leukemia (AML).
- Brain and spinal cord tumors.
- Head and neck cancer.
- Hodgkin lymphoma.
- Non-Hodgkin lymphoma.
- Wilms tumor.
Cancers treated with a stem cell transplant.

Radiation to the chest and certain types of chemotherapy increase the risk of heart and blood vessel late effects.

The risk of health problems involving the heart and blood vessels increases after treatment with the following:

- **Radiation** to the chest, spine, brain, neck, kidneys, or total-body irradiation (TBI) as part of a stem cell transplant. The risk of problems depends on the area of the body that was exposed to radiation, the amount of radiation given, and whether the radiation was given in small or large doses.
- **Certain types of chemotherapy** and the total dose of anthracycline given. Chemotherapy with anthracyclines such as doxorubicin, daunorubicin, idarubicin, and epirubicin, and with anthraquinones such as mitoxantrone increase the risk of heart and blood vessel problems. The risk of problems depends on the total dose of chemotherapy given and the type of drug used. It also depends on whether treatment with anthracyclines was given to a child younger than 13 years and whether a drug called dexrazoxane was given during treatment with anthracyclines. Dexrazoxane may lessen heart and blood vessel damage up to 5 years after treatment. Ifosfamide, methotrexate, and chemotherapy with platinum, such as carboplatin and cisplatin, may also cause heart and blood vessel late effects.
- **Stem cell transplant.**
- **Nephrectomy** (surgery to remove all or part of a kidney).

Childhood cancer survivors who were treated with radiation to the heart or blood vessels and certain types of chemotherapy are at greatest risk.

New treatments that decrease the amount of radiation given and use lower doses of chemotherapy or less harmful chemotherapy drugs may lessen the risk of heart and blood vessel late effects compared with older treatments.

The following may also increase the risk of heart and blood vessel late effects:

- Longer time since treatment.
- Having high blood pressure or other risk factors for heart disease, such as a family history of heart disease, being overweight, smoking, high cholesterol, or diabetes. When these risk factors are combined, the risk of late effects is even higher.
- Having lower than normal amounts of thyroid, growth, or sex hormones.

Late effects that affect the heart and blood vessels may cause certain health problems.

Childhood cancer survivors who received radiation or certain types of chemotherapy have an increased risk of late effects to the heart and blood vessels and related health problems. These include the following:
• Abnormal heartbeat.
• Weakened heart muscle.
• Inflamed heart or sac around the heart.
• Damage to the heart valves.
• Coronary artery disease (hardening of the heart arteries).
• Congestive heart failure.
• Chest pain or heart attack.
• Blood clots or one or more strokes.
• Carotid artery disease.

Possible signs and symptoms of heart and blood vessel late effects include trouble breathing and chest pain.

These and other signs and symptoms may be caused by heart and blood vessel late effects or by other conditions:

• Trouble breathing, especially when lying down.
• Heartbeat that is too slow, too fast, or different from the heart's normal rhythm.
• Chest pain or pain in the arm or leg.
• Swelling of the feet, ankles, legs, or abdomen.
• When exposed to cold or having strong emotions, the fingers, toes, ears, or nose become white and then turn blue. When this happens to the fingers, there may also be pain and tingling.
• Sudden numbness or weakness of the face, arm, or leg (especially on one side of the body).
• Sudden confusion or trouble speaking or understanding speech.
• Sudden trouble seeing with one or both eyes.
• Sudden trouble walking or feeling dizzy.
• Sudden loss of balance or coordination.
• Sudden severe headache for no known reason.
• Pain, warmth, or redness in one area of the arm or leg, especially the back of the lower leg.

Talk to your child's doctor if your child has any of these problems.

Certain tests and procedures are used to diagnose health problems in the heart and blood vessels.

These and other tests and procedures may be used to detect or diagnose heart and blood vessel late effects:

• **Physical exam and health history:** An exam of the body to check general signs of health, including checking the heart for signs of disease, such as abnormal heart beat, high blood pressure, or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
• **Electrocardiogram (EKG):** A recording of the heart's electrical activity to check its rate and rhythm. A number of small pads (electrodes) are placed on the patient’s chest, arms, and legs, and are connected by wires to the EKG machine. Heart activity is then recorded as a line graph on
paper. Electrical activity that is faster or slower than normal may be a sign of heart disease or damage.

- **Echocardiogram**: A procedure in which high-energy sound waves (ultrasound) are bounced off the heart and nearby tissues or organs and make echoes. A moving picture is made of the heart and heart valves as blood is pumped through the heart.
- **Ultrasound exam**: A procedure in which high-energy sound waves (ultrasound) are bounced off internal tissues or organs such as the heart and make echoes. The echoes form a picture of body tissues called a sonogram. The picture can be printed to be looked at later.
- **CT scan (CAT scan)**: A procedure that makes a series of detailed pictures of areas inside the body, taken from different angles. The pictures are made by a computer linked to an x-ray machine. A dye may be injected into a vein or swallowed to help the organs or tissues show up more clearly. This procedure is also called computed tomography, computerized tomography, or computerized axial tomography. This procedure is done to check for blood clots.
- **Lipid profile studies**: A procedure in which a blood sample is checked to measure the amounts of triglycerides, cholesterol, and low- and high-density lipoprotein cholesterol in the blood.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of heart and blood vessel late effects. If tests are needed, find out how often they should be done.

**Health habits that promote a healthy heart and blood vessels are important for survivors of childhood cancer.**

Childhood cancer survivors may lower the risk of heart and blood vessel late effects by having a healthy lifestyle, which includes:

- A healthy weight.
- A heart-healthy diet.
- Regular exercise.
- Not smoking.

**Central Nervous System**

**Brain and spinal cord late effects are more likely to occur after treatment for certain childhood cancers.**

Treatment for these and other childhood cancers may cause brain and spinal cord late effects:

- Acute lymphoblastic leukemia (ALL).
- Brain and spinal cord tumors.
- Head and neck cancers, including retinoblastoma.
- Non-Hodgkin lymphoma.
- Osteosarcoma.

**Radiation to the brain increases the risk of brain and spinal cord late effects.**
The risk of health problems that affect the brain or spinal cord increases after treatment with the following:

- Radiation to the brain or spinal cord, especially high doses of radiation. This includes total-body irradiation given as part of a stem cell transplant.
- Intrathecal or intraventricular chemotherapy.
- Chemotherapy with high-dose methotrexate or cytarabine that can cross the blood-brain barrier (protective lining around the brain). This includes high-dose chemotherapy given as part of a stem cell transplant.
- Surgery to remove a tumor on the brain or spinal cord.

When radiation to the brain and intrathecal chemotherapy are given at the same time, the risk of late effects is higher.

The following may also increase the risk of brain and spinal cord late effects in childhood brain tumor survivors:

- Being about 5 years old or younger at the time of treatment.
- Being female.
- Having hydrocephalus and a shunt placed to remove the extra fluid from the ventricles.
- Having hearing loss.
- Having cerebellar mutism following surgery to remove the brain tumor. Cerebellar mutism includes not being able to speak, loss of coordination and balance, mood swings, being irritable, and having a high-pitched cry.
- Having a personal history of stroke.
- Seizures.

Central nervous system late effects are also affected by where the tumor has formed in the brain and spinal cord.

**Late effects that affect the brain and spinal cord may cause certain health problems.**

Childhood cancer survivors who received radiation, certain types of chemotherapy, or surgery to the brain or spinal cord have an increased risk of late effects to the brain and spinal cord and related health problems. These include the following:

- Headaches.
- Loss of coordination and balance.
- Dizziness.
- Seizures.
- Loss of the myelin sheath that covers nerve fibers in the brain.
• Movement disorders that affect the legs and eyes or the ability to speak and swallow.
• Nerve damage in the hands or feet.
• Stroke. A second stroke may be more likely in survivors who received radiation to the brain, have a history of high blood pressure, or were older than 40 years when they had their first stroke.
• Daytime sleepiness.
• Hydrocephalus.
• Loss of bladder and/or bowel control.
• Cavernomas (clusters of abnormal blood vessels).
• Back pain.

Survivors may also have late effects that affect thinking, learning, memory, emotions, and behavior.

New ways of using more targeted and lower doses of radiation to the brain may lessen the risk of brain and spinal cord late effects.

**Possible signs and symptoms of brain and spinal cord late effects include headaches, loss of coordination, and seizures.**

These signs and symptoms may be caused by brain and spinal cord late effects or by other conditions:

• Headache that may go away after vomiting.
• Seizures.
• Loss of balance, lack of coordination, or trouble walking.
• Trouble speaking or swallowing.
• Trouble with having the eyes work together.
• Numbness, tingling, or weakness in the hands or feet.
• Being unable to bend the ankle to lift the foot up.
• Sudden numbness or weakness of the face, arm, or leg (especially on one side of the body).
• Unusual sleepiness or change in activity level.
• Unusual changes in personality or behavior.
• A change in bowel habits or trouble urinating.
• Increase in head size (in infants).
• Sudden confusion or trouble speaking or understanding speech.
• Sudden trouble seeing with one or both eyes.
• Sudden severe headache for no known reason.

Other signs and symptoms include the following:

• Problems with memory.
• Problems with paying attention.
• Trouble with solving problems.
• Trouble with organizing thoughts and tasks.
• Slower ability to learn and use new information.
• Trouble learning to read, write, or do math.
- Trouble coordinating movement between the eyes, hands, and other muscles.
- Delays in normal development.
- Social withdrawal or trouble getting along with others.

Talk to your child's doctor if your child has any of these problems.

**Certain tests and procedures are used to diagnose health problems in the brain and spinal cord.**

These and other tests and procedures may be used to detect or diagnose brain and spinal cord late effects:

- **Physical exam and health history:** An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Neurological exam:** A series of questions and tests to check the brain, spinal cord, and nerve function. The exam checks a person’s mental status, coordination, and ability to walk normally, and how well the muscles, senses, and reflexes work. This may also be called a neuro exam or a neurologic exam. In some cases, a more complete exam may be done by a neurologist or neurosurgeon.
- **Neuropsychological assessment:** A series of tests to examine the patient's mental processes and behavior. Areas that are checked usually include:
  - Knowing who and where you are and what day it is.
  - Ability to learn and remember new information.
  - Intelligence.
  - Ability to solve problems.
  - Use of spoken and written language.
  - Eye-hand coordination.
  - Ability to organize information and tasks.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of brain and spinal cord late effects. If tests are needed, find out how often they should be done.

**Survivors of childhood cancer may have anxiety and depression related to their cancer.**

Survivors of childhood cancer may have anxiety and depression related to physical changes, having pain, the way they look, or the fear of cancer coming back. These and other factors may cause problems with personal relationships, education, employment, and health, and cause thoughts of suicide. Survivors with these problems may be less likely to live on their own as adults.

Follow-up exams for childhood cancer survivors should include screening and treatment for possible psychological distress, such as anxiety, depression, and thoughts of suicide.

**Some childhood cancer survivors have post-traumatic stress disorder.**
Being diagnosed and treated for a life-threatening disease may be traumatic. This trauma may cause post-traumatic stress disorder (PTSD). PTSD is defined as having certain behaviors following a stressful event that involved death or the threat of death, serious injury, or a threat to oneself or others.

PTSD can affect cancer survivors in the following ways:

- Reliving the time they were diagnosed and treated for cancer, in nightmares or flashbacks, and thinking about it all the time.
- Avoiding places, events, and people that remind them of the cancer experience.

In general, childhood cancer survivors show low levels of PTSD, depending in part on the coping style of patients and their parents. Survivors who received radiation therapy to the head when younger than 4 years or survivors who received intensive treatment may be at higher risk of PTSD. Family problems, little or no social support from family or friends, and stress not related to the cancer may increase the chances of having PTSD.

Because avoiding places and persons connected to the cancer may be part of PTSD, survivors with PTSD may not get the medical treatment they need.

**Adolescents who are diagnosed with cancer may have social problems later in life.**

Adolescents who are diagnosed with cancer may reach fewer social milestones or reach them later in life than adolescents not diagnosed with cancer. Social milestones include having a first boyfriend or girlfriend, getting married, and having a child. They may also have trouble getting along with other people or feel like they are not liked by others their age.

Cancer survivors in this age group have reported being less satisfied with their health and their lives in general compared with others of the same age who did not have cancer. Adolescents and young adults who have survived cancer need special programs that give psychological, educational, and job support.

**Digestive System**

**Teeth and Jaws**

Problems with the teeth and jaws are late effects that are more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause the late effect of problems with teeth and jaws:

- Head and neck cancers.
- Hodgkin lymphoma.
- Neuroblastoma.
Radiation to the head and neck and certain types of chemotherapy increase the risk of late effects to the teeth and jaws.

The risk of health problems that affect the teeth and jaws increases after treatment with the following:

- Radiation therapy to the head and neck.
- Total-body irradiation (TBI) as part of a stem cell transplant.
- Chemotherapy, especially with higher doses of alkylating agents such as cyclophosphamide.
- Surgery in the head and neck area.

Risk is also increased in survivors who were younger than 5 years at the time of treatment because their permanent teeth had not fully formed.

**Late effects that affect the teeth and jaws may cause certain health problems.**

Teeth and jaw late effects and related health problems include the following:

- Teeth that are not normal.
- Tooth decay (including cavities) and gum disease.
- Salivary glands do not make enough saliva.
- Death of the bone cells in the jaw.
- Changes in the way the face, jaw, or skull form.

**Possible signs and symptoms of late effects of the teeth and jaws include tooth decay (cavities) and jaw pain.**

These and other signs and symptoms may be caused by late effects of the teeth and jaws or by other conditions:

- Teeth are small or do not have a normal shape.
- Missing permanent teeth.
- Permanent teeth come in at a later than normal age.
- Teeth have less enamel than normal.
- More tooth decay (cavities) and gum disease than normal.
- Dry mouth.
- Trouble chewing, swallowing, and speaking.
- Jaw pain.
- Jaws do not open and close the way they should.

Talk to your child's doctor if your child has any of these problems.
Certain tests and procedures are used to diagnose health problems in the mouth and jaws.

These and other tests and procedures may be used to detect or diagnose late effects of the teeth and jaws:

- **Dental exam and health history**: An exam of the teeth, mouth, and jaws to check general signs of dental health, including checking for signs of disease, such as cavities or anything that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken. This may also be called a dental check-up.
- **Panorex x-ray**: An x-ray of all of the teeth and their roots. An x-ray is a type of energy beam that can go through the body and onto film, making a picture of areas inside the body.
- **X-ray of the jaws**: An x-ray of the jaws. An x-ray is a type of energy beam that can go through the body and onto film, making a picture of areas inside the body.
- **CT scan (CAT scan)**: A procedure that makes a series of detailed pictures of areas inside the body, such as the head and neck, taken from different angles. The pictures are made by a computer linked to an x-ray machine. This procedure is also called computed tomography, computerized tomography, or computerized axial tomography.
- **MRI (magnetic resonance imaging)**: A procedure that uses a magnet, radio waves, and a computer to make a series of detailed pictures of areas inside the body, such as the head and neck. This procedure is also called nuclear magnetic resonance imaging (NMRI).
- **Biopsy**: The removal of bone cells from the jaw so they can be viewed under a microscope to check for signs of bone death after radiation therapy.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of teeth and jaw late effects. If tests are needed, find out how often they should be done.

**Regular dental care is very important for survivors of childhood cancer.**

Doctors suggest that survivors of childhood cancer have a dental check-up and a cleaning and fluoride treatment every 6 months. Children who had radiation therapy to the oral cavity may also see an orthodontist or an otolaryngologist. If lesions are present in the mouth, a biopsy may be needed.

**Digestive Tract**

Digestive tract late effects are more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause late effects of the digestive tract (esophagus, stomach, small and large intestines, rectum and anus):

- Rhabdomyosarcoma of the bladder or prostate, or near the testicles.
- Non-Hodgkin lymphoma.
- Germ cell tumors.
- Neuroblastoma.
- Wilms tumor.
Radiation to the bladder, prostate, or testicles and certain types of chemotherapy increase the risk of digestive tract late effects.

The risk of health problems that affect the digestive tract increases after treatment with the following:

- Radiation therapy to the abdomen or areas near the abdomen, such as the esophagus, bladder, prostate, or testicles, may cause digestive tract problems that begin quickly and last for a short time. In some patients, however, digestive tract problems are delayed and long-lasting. These late effects are caused by radiation therapy that damages the blood vessels. Receiving higher doses of radiation therapy or receiving chemotherapy such as dactinomycin or anthracyclines together with radiation therapy may increase this risk.
- Abdominal surgery or pelvic surgery to remove the bladder.
- Chemotherapy with alkylating agents such as cyclophosphamide, procarbazine, and ifosfamide, or with platinum agents such as cisplatin or carboplatin, or with anthracyclines such as doxorubicin, daunorubicin, idarubicin, and epirubicin.
- Stem cell transplant.

The following may also increase the risk of digestive tract late effects:

- Older age at diagnosis or when treatment begins.
- Treatment with both radiation therapy and chemotherapy.
- A history of chronic graft-versus-host disease.

Late effects that affect the digestive tract may cause certain health problems.

Digestive tract late effects and related health problems include the following:

- A narrowing of the esophagus or intestine.
- The muscles of the esophagus do not work well.
- Reflux
  - Diarrhea, constipation, fecal incontinence, or blocked bowel.
  - Bowel perforation (a hole in the intestine).
  - Inflammation of the intestines.
  - Death of part of the intestine.
  - Intestine is not able to absorb nutrients from food.

Possible signs and symptoms of digestive tract late effects include abdominal pain and diarrhea.

These and other signs and symptoms may be caused by digestive tract late effects or by other conditions:
- A change in bowel habits (constipation or diarrhea).
- Nausea and vomiting.
- Frequent gas pains, bloating, fullness, or cramps.
- Hemorrhoids.
- Reflux.

Talk to your child's doctor if your child has any of these problems.

**Certain tests and procedures are used to diagnose health problems in the digestive tract.**

These and other tests and procedures may be used to detect or diagnose digestive tract late effects:

- **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as abdominal tenderness or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Digital rectal exam**: An exam of the rectum. The doctor or nurse inserts a lubricated, gloved finger into the rectum to feel for lumps or anything else that seems unusual.
- **Blood chemistry studies**: A procedure in which a blood sample is checked to measure the amounts of certain substances released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease.
- **X-ray**: An x-ray is a type of energy beam that can go through the body and onto film, making a picture of areas inside the body. An x-ray may be taken of the abdomen, kidney, ureter, or bladder to check for signs of disease.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of digestive tract late effects. If tests are needed, find out how often they should be done.

**Liver and Bile Ducts**

Liver and bile duct late effects are more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause liver or bile duct late effects:

- Liver cancer.
- Wilms tumor.
- Acute lymphoblastic leukemia (ALL).
- Cancers treated with a stem cell transplant.

Certain types of chemotherapy and radiation to the liver or bile ducts increase the risk of late effects.
The risk of liver or bile duct late effects may be increased in childhood cancer survivors treated with one of the following:

- Surgery to remove part of the liver or a liver transplant.
- Chemotherapy that includes high-dose cyclophosphamide as part of a stem cell transplant.
- Chemotherapy such as 6-mercaptopurine, 6-thioguanine, and methotrexate.
- Radiation therapy to the liver and bile ducts. The risk depends on the following:
  - The dose of radiation and how much of the liver is treated.
  - Age when treated (the younger the age, the higher the risk).
  - Whether there was surgery to remove part of the liver.
  - Whether chemotherapy, such as doxorubicin or dactinomycin, was given together with radiation therapy.
- Stem cell transplant (and a history of chronic graft-versus-host disease).

**Late effects that affect the liver and bile ducts may cause certain health problems.**

Liver and bile duct late effects and related health problems include the following:

- Liver doesn’t work the way it should or stops working.
- Gallstones.
- Benign liver lesions.
- Hepatitis B or C infection.
- Liver damage caused by veno-occlusive disease/sinusoidal obstruction syndrome (VOD/SOS).
- Liver fibrosis (an overgrowth of connective tissue in the liver) or cirrhosis.
- Fatty liver with insulin resistance (a condition in which the body makes insulin but cannot use it well).
- Tissue and organ damage from the buildup of extra iron after having many blood transfusions.

**Possible signs and symptoms of liver and bile duct late effects include abdominal pain and jaundice.**

These and other signs and symptoms may be caused by liver and bile duct late effects or by other conditions:

- Weight gain or weight loss.
- Swelling of the abdomen.
- Nausea and vomiting.
- Pain in the abdomen. Pain may occur near the ribs, often on the right side, or after eating a fatty meal.
- Jaundice (yellowing of the skin and whites of the eyes).
- Light-colored bowel movements.
- Dark-colored urine.
- A lot of gas.
- Lack of appetite.
Feeling tired or weak.

Talk to your child's doctor if your child has any of these problems.

Sometimes there are no signs or symptoms of liver or bile duct late effects and treatment may not be needed.

**Certain tests and procedures are used to diagnose health problems in the liver and bile duct.**

These and other tests and procedures may be used to detect or diagnose liver or bile duct late effects:

- **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.

- **Blood chemistry studies**: A procedure in which a blood sample is checked to measure the amounts of certain substances released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease. For example, there may be a higher level of bilirubin, alanine aminotransferase (ALT), and aspartate aminotransferase (AST) in the body if the liver has been damaged.

- **Ferritin level**: A procedure in which a blood sample is checked to measure the amount of ferritin. Ferritin is a protein that binds to iron and stores it for use by the body. After a stem cell transplant, a high ferritin level may be a sign of liver disease.

- **Blood studies to check how well the blood clots**: A procedure in which a blood sample is checked to measure the amount of platelets in the body or how long it takes for the blood to clot.

- **Hepatitis assay**: A procedure in which a blood sample is checked for pieces of the hepatitis virus. The blood sample may also be used to measure how much hepatitis virus is in the blood. All patients who had a blood transfusion before 1972 should have a screening test for hepatitis B. Patients who had a blood transfusion before 1993 should have a screening test for hepatitis C.

- **Ultrasound exam**: A procedure in which high-energy sound waves (ultrasound) are bounced off internal tissues or organs, such as the gallbladder, and make echoes. The echoes form a picture of body tissues called a sonogram. The picture can be printed to be looked at later.

- **Biopsy**: The removal of cells or tissues from the liver so they can be viewed under a microscope to check for signs of a fatty liver.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of liver or bile duct late effects. If tests are needed, find out how often they should be done.

**Health habits that promote a healthy liver are important for survivors of childhood cancer.**

Childhood cancer survivors with liver late effects should take care to protect their health, including:

- Having a healthy weight.
- Not drinking alcohol.
● Getting vaccines for hepatitis A and hepatitis B viruses.

**Pancreas**

**Radiation therapy increases the risk of pancreatic late effects.**

The risk of pancreatic late effects may be increased in childhood cancer survivors after treatment with one of the following:

- Radiation therapy to the abdomen.
- Total-body irradiation (TBI) as part of a stem cell transplant.

**Late effects that affect the pancreas may cause certain health problems.**

Pancreatic late effects and related health problems include the following:

- **Insulin resistance**: A condition in which the body does not use insulin the way it should. Insulin is needed to help control the amount of glucose (a type of sugar) in the body. Because the insulin does not work the way it should, glucose and fat levels rise.
- **Diabetes mellitus**: A disease in which the body does not make enough insulin or does not use it the way it should. When there is not enough insulin, the amount of glucose in the blood increases and the kidneys make a large amount of urine.

**Possible signs and symptoms of pancreatic late effects include frequent urination and being thirsty.**

These and other signs and symptoms may be caused by pancreatic late effects or by other conditions:

- Frequent urination.
- Feeling very thirsty.
- Feeling very hungry.
- Weight loss for no known reason.
- Feeling very tired.
- Frequent infections, especially of the skin, gums, or bladder.
- Blurred vision.
- Cuts or bruises that are slow to heal.
- Numbness or tingling in the hands or feet.

Talk to your child's doctor if your child has any of these problems.

**Certain tests and procedures are used to diagnose health problems in the pancreas.**

These and other tests and procedures may be used to detect or diagnose pancreatic late effects:
- **Glycated hemoglobin (A1C) test**: A procedure in which a sample of blood is drawn and the amount of glucose that is attached to red blood cells is measured. A higher than normal amount of glucose attached to red blood cells can be a sign of diabetes mellitus.
- **Fasting blood sugar test**: A test in which a blood sample is checked to measure the amount of glucose in the blood. This test is done after the patient has had nothing to eat overnight. A higher than normal amount of glucose in the blood can be a sign of diabetes mellitus.

### Endocrine System

#### Thyroid Gland

Thyroid late effects are more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause thyroid late effects:

- Acute lymphoblastic leukemia (ALL).
- Brain tumors.
- Head and neck cancers.
- Hodgkin lymphoma.
- Neuroblastoma.
- Cancers treated with a stem cell transplant.

**Radiation therapy to the head and neck increases the risk of thyroid late effects.**

The risk of thyroid late effects may be increased in childhood cancer survivors after treatment with any of the following:

- Radiation therapy to the thyroid as part of radiation therapy to the head and neck or to the pituitary gland in the brain.
- Total-body irradiation (TBI) as part of a stem cell transplant.
- MIBG (radioactive iodine) therapy for neuroblastoma.

The risk also is increased in females, in survivors who were a young age at the time of treatment, in survivors who had a higher radiation dose, and as the time since diagnosis and treatment gets longer.

**Late effects that affect the thyroid may cause certain health problems.**

Thyroid late effects and related health problems include the following:

- **Hypothyroidism (not enough thyroid hormone)**: This is the most common thyroid late effect. It usually occurs 2 to 5 years after treatment ends but may occur later. It is more common in girls than boys.
Hyperthyroidism (too much thyroid hormone): It usually occurs 3 to 5 years after treatment ends.
Goiter (an enlarged thyroid).
Lumps in the thyroid: Usually occur 10 or more years after treatment ends. It is more common in girls than boys. These growths may be benign (not cancerous) or malignant (cancer).

Signs and symptoms of thyroid late effects depend on whether there is too little or too much thyroid hormone in the body.

These and other signs and symptoms may be caused by thyroid late effects or by other conditions:

**Hypothyroidism (too little thyroid hormone)**

- Feeling tired or weak.
- Being more sensitive to cold.
- Pale, dry skin.
- Coarse and thinning hair.
- Brittle fingernails.
- Hoarse voice.
- Puffy face.
- Muscle and joint aches and stiffness.
- Constipation.
- Menstrual periods that are heavier than normal.
- Weight gain for no known reason.
- Depression or trouble with memory or being able to concentrate.

Rarely, hypothyroidism does not cause any symptoms.

**Hyperthyroidism (too much thyroid hormone)**

- Feeling nervous, anxious, or moody.
- Trouble sleeping.
- Feeling tired or weak.
- Having shaky hands.
- Having a fast heartbeat.
- Having red, warm skin that may be itchy.
- Having fine, soft hair that is falling out.
- Having frequent or loose bowel movements.
- Weight loss for no known reason.

Talk to your child's doctor if your child has any of these problems.

Certain tests and procedures are used to diagnose health problems in the thyroid.
These and other tests and procedures may be used to detect or diagnose thyroid late effects:

- **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Blood hormone studies**: A procedure in which a blood sample is checked to measure the amounts of certain hormones released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease in the organ or tissue that makes it. The blood may be checked for abnormal levels of thyroid-stimulating hormone (TSH) or free thyroxine (T4).
- **Ultrasound exam**: A procedure in which high-energy sound waves (ultrasound) are bounced off internal tissues or organs and make echoes. The echoes form a picture of body tissues called a sonogram. The picture can be printed to be looked at later. This procedure can show the size of the thyroid and whether there are nodules (lumps) on the thyroid.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of thyroid late effects. If tests are needed, find out how often they should be done.

**Pituitary Gland**

Neuroendocrine late effects may be caused after treatment for certain childhood cancers.

The neuroendocrine system is the nervous system and the endocrine system working together.

Treatment for these and other childhood cancers may cause neuroendocrine late effects:

- Brain and spinal cord tumors.
- Acute lymphoblastic leukemia (ALL).
- Nasopharyngeal cancer.
- Cancers treated with total-body irradiation (TBI) before a stem cell transplant.

**Treatment that affects the hypothalamus or pituitary gland increases the risk of neuroendocrine system late effects.**

Childhood cancer survivors have an increased risk for neuroendocrine late effects. These effects are caused by radiation therapy to the brain in the area of the hypothalamus. The hypothalamus controls the way hormones are made and released into the bloodstream by the pituitary gland. Radiation therapy may be given to treat cancer near the hypothalamus or as total-body irradiation (TBI) before a stem cell transplant. These effects are also caused by surgery in the area of the hypothalamus, pituitary gland, or optic pathways.

Childhood cancer survivors who have neuroendocrine late effects may have low levels of any of the following hormones made in the pituitary gland and released into the blood:
• Growth hormone (GH; helps promote growth and control metabolism).
• Adrenocorticotropic hormone (ACTH; controls the making of glucocorticoids).
• Prolactin (controls the making of breast milk).
• Thyroid-stimulating hormone (TSH; controls the making of thyroid hormones).
• Luteinizing hormone (LH; controls reproduction).
• Follicle-stimulating hormone (FSH; controls reproduction).

Late effects that affect the hypothalamus may cause certain health problems.

Neuroendocrine late effects and related health problems include the following:

• **Growth hormone deficiency**: A low level of growth hormone is a common late effect of radiation to the brain in childhood cancer survivors. The higher the radiation dose and the longer the time since treatment, the greater the risk of this late effect. A low level of growth hormone may also occur in childhood ALL and stem cell transplant survivors who received radiation therapy to the brain and spinal cord and/or chemotherapy. A low level of growth hormone in childhood results in adult height that is shorter than normal. If the child's bones have not fully developed, low growth hormone levels may be treated with growth hormone replacement therapy beginning one year after the end of treatment.

• **Adrenocorticotropic deficiency**: A low level of adrenocorticotropic hormone is an uncommon late effect. It may occur in childhood brain tumor survivors, survivors with low growth hormone levels or central hypothyroidism, or after radiation therapy to the brain. Symptoms of deficiency may not be severe and may not be noticed. Signs and symptoms of adrenocorticotropic deficiency include the following:
  o Weight loss for no known reason.
  o Not feeling hungry.
  o Nausea.
  o Vomiting.
  o Low blood pressure.
  o Feeling tired.

Low levels of adrenocorticotropic hormone may be treated with hydrocortisone therapy.

• **Hyperprolactinemia**: A high level of the hormone prolactin may occur after a high dose of radiation to the brain or surgery that affects part of the pituitary gland. A high level of prolactin may cause the following:
  o Puberty at a later age than normal.
  o Flow of breast milk in a woman who is not pregnant or breast-feeding.
  o Less frequent or no menstrual periods or menstrual periods with a very light flow.
  o Hot flashes (in women).
  o Inability to become pregnant.
  o Inability to have an erection needed for sexual intercourse.
  o Lower sex drive (in men and women).
  o Osteopenia (low bone mineral density).

Sometimes there are no signs and symptoms. Treatment is rarely needed.
- **Thyroid-stimulating hormone deficiency** (central hypothyroidism): A low level of thyroid hormone may occur very slowly over time after radiation therapy to the brain. Sometimes the symptoms of thyroid-stimulating hormone deficiency are not noticed. Low thyroid hormone levels may cause slow growth and delayed puberty, as well as other symptoms. A low level of thyroid hormone may be treated with thyroid hormone replacement therapy.

- **Luteinizing hormone or follicle-stimulating hormone deficiency**: Low levels of these hormones can cause different health problems. The type of problem depends on the radiation dose. Childhood cancer survivors who were treated with lower doses of radiation to the brain may develop central precocious puberty (a condition that causes puberty to start before age 8 years in girls and 9 years in boys). This condition may be treated with gonadotropin-releasing hormone (GnRH) agonist therapy to delay puberty and help the child's growth. Hydrocephalus may also increase the risk of this late effect.

  Childhood cancer survivors who were treated with higher doses of radiation to the brain may have low levels of luteinizing hormone or follicle-stimulating hormone. This condition may be treated with sex hormone replacement therapy. The dose will depend on the child's age and whether the child has reached puberty.

- **Central diabetes insipidus**: Central diabetes insipidus may be caused by the absence of or low amounts of all of the hormones made in the front part of the pituitary gland and released into the blood. It may occur in childhood cancer survivors treated with surgery in the area of the hypothalamus or pituitary gland. Signs and symptoms of central diabetes insipidus may include the following:
  - Having large amounts of urine or unusually wet diapers.
  - Feeling very thirsty.
  - Headache.
  - Trouble with vision.
  - Slowed growth and development.
  - Weight loss for no known reason.

  Treatment may include hormone replacement therapy with vasopressin, the hormone that controls the amount of urine that is made in the body.

**Certain tests and procedures are used to diagnose health problems in the neuroendocrine system.**

These and other tests and procedures may be used to detect or diagnose thyroid late effects:

- **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.

- **Blood chemistry study**: A procedure in which a blood sample is checked to measure the amounts of certain substances, such as glucose, released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease.
- **Blood hormone studies**: A procedure in which a blood sample is checked to measure the amounts of certain hormones released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease in the organ or tissue that makes it. The blood may be checked for abnormal levels of follicle-stimulating hormone, luteinizing hormone, estradiol, testosterone, cortisol, or free thyroxine (T4).
- **Lipid profile studies**: A procedure in which a blood sample is checked to measure the amounts of triglycerides, cholesterol, and low- and high-density lipoprotein cholesterol in the blood.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of neuroendocrine late effects. If tests are needed, find out how often they should be done.

**Testicles and Ovaries**

See the [Reproductive System](#) section of this summary for information about late effects in the testicles and ovaries.

**Metabolic Syndrome**

**Metabolic syndrome is more likely to occur after treatment for certain childhood cancers.**

Metabolic syndrome is a group of medical conditions that includes having too much fat around the abdomen and at least two of the following:
- High blood pressure.
- High levels of triglycerides and low levels of high-density lipoprotein (HDL) cholesterol in the blood.
- High levels of glucose (sugar) in the blood.

Treatment for these and other childhood cancers may cause metabolic syndrome to occur later in life:
- Acute lymphoblastic leukemia (ALL).
- Cancers treated with a stem cell transplant.
- Cancers treated with radiation to the abdomen, such as Wilms tumor or neuroblastoma.

**Radiation therapy increases the risk of metabolic syndrome.**

The risk of metabolic syndrome may be increased in childhood cancer survivors after treatment with any of the following:
- Radiation therapy to the brain or abdomen.
- Total-body irradiation (TBI) as part of a stem cell transplant.

**Certain tests and procedures are used to diagnose metabolic syndrome.**

These and other tests and procedures may be used to detect or diagnose metabolic syndrome:
• **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.

• **Blood chemistry studies**: A procedure in which a blood sample is checked to measure the amounts of certain substances, such as glucose, released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease.

• **Lipid profile studies**: A procedure in which a blood sample is checked to measure the amounts of triglycerides, cholesterol, and low- and high-density lipoprotein cholesterol in the blood.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of metabolic syndrome. If tests are needed, find out how often they should be done.

**Metabolic syndrome may cause heart and blood vessel disease and diabetes.**

Metabolic syndrome is linked to an increased risk of heart and blood vessel disease and diabetes. Health habits that decrease these risks include:

- Having a healthy weight.
- Eating a heart-healthy diet.
- Having regular exercise.
- Not smoking.

**Weight**

**Being underweight, overweight, or obese is a late effect that is more likely to occur after treatment for certain childhood cancers.**

Treatment for these and other childhood cancers may cause a change in weight:

- Acute lymphoblastic leukemia (ALL).
- Brain tumors, especially craniopharyngiomas.
- Cancers treated with radiation to the brain, including total-body irradiation (TBI) as part of a stem cell transplant.

**Radiation therapy increases the risk of being underweight, overweight, or obese.**

The risk of being underweight increases after treatment with the following:

- Total-body irradiation (TBI) for females.
- Radiation therapy to the abdomen for males.
- Certain types of chemotherapy (alkylating agents and anthracyclines).

The risk of obesity increases after treatment with the following:

- Radiation therapy to the brain.
- Surgery that damages the hypothalamus or pituitary gland, such as surgery to remove a craniopharyngioma brain tumor.

The following may also increase the risk of obesity:
- Being diagnosed with cancer when aged 5 to 9 years.
- Being female.
- Having growth hormone deficiency or low levels of the hormone leptin.
- Not doing enough physical activity to stay at a healthy body weight.
- Taking an antidepressant called paroxetine.

Childhood cancer survivors who get enough exercise and have a normal amount of anxiety have a lower risk of obesity.

**Certain tests and procedures are used to diagnose a change in weight.**

These and other tests and procedures may be used to detect or diagnose a change in weight:

- **Physical exam and health history**: An exam of the body to check general signs of health, including weight or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Blood chemistry studies**: A procedure in which a blood sample is checked to measure the amounts of certain substances, such as glucose, released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance can be a sign of disease.
- **Lipid profile studies**: A procedure in which a blood sample is checked to measure the amounts of triglycerides, cholesterol, and low- and high-density lipoprotein cholesterol in the blood.

Being underweight, overweight, or obese may be measured by weight, body mass index, percent of body fat, or size of the abdomen (belly fat).

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of a change in weight. If tests are needed, find out how often they should be done.

**Immune System**

**Surgery to remove the spleen increases the risk of immune system late effects.**

The risk of health problems that affect the immune system increases after treatment with the following:
- Surgery to remove the spleen.
- High-dose radiation therapy to the spleen which causes the spleen to stop working.
- Stem cell transplant followed by graft-versus-host disease which causes the spleen to stop working.

Late effects that affect the immune system may cause infection.
Late effects that affect the immune system may increase the risk of very serious bacterial infections. This risk is higher in younger children than in older children and may be greater in the early years after the spleen stops working or is removed by surgery. These signs and symptoms may be caused by infection:

- Redness, swelling, or warmth of a part of the body.
- Pain that is in one part of the body, such as the eye, ear, or throat.
- Fever.

An infection may cause other symptoms that depend on the part of the body affected. For example, a lung infection may cause a cough and trouble breathing.

**Children who have had their spleen removed may need antibiotics to lessen the risk of infection.**

Daily antibiotics may be prescribed for children younger than 5 years of age whose spleen is no longer working or for at least 1 year after surgery to remove the spleen. For certain high-risk patients, daily antibiotics may be prescribed throughout childhood and into adulthood.

In addition, children with an increased risk of infection should be vaccinated on a schedule through adolescence against the following:

- Pneumococcal disease.
- Meningococcal disease.
- *Haemophilus influenzae* type b (Hib) disease.
- Diphtheria-tetanus-pertussis (DTaP).
- Hepatitis B.

Talk to your child's doctor about whether other childhood vaccinations given before cancer treatment need to be repeated.

**Musculoskeletal System**

**Bone and joint late effects are more likely to occur after treatment for certain childhood cancers.**

Treatment for these and other childhood cancers may cause bone and joint late effects:

- Acute lymphoblastic leukemia (ALL).
- Bone cancer.
- Brain and spinal cord tumors.
- Ewing sarcoma.
- Head and neck cancers.
- Neuroblastoma.
- Non-Hodgkin lymphoma.
- Osteosarcoma.
- Retinoblastoma.
- Soft tissue sarcoma.
- Wilms tumor.
- Cancers treated with a stem cell transplant.

Poor nutrition and not enough exercise may also cause bone late effects.

**Surgery, chemotherapy, radiation therapy, and other treatments increase the risk of bone and joint late effects.**

**Radiation therapy**

Radiation therapy can stop or slow the growth of bone. The type of bone and joint late effect depends on the part of the body that received radiation therapy. Radiation therapy may cause any of the following:

- Changes in the way the face or skull form, especially when **high-dose radiation** with or without **chemotherapy** is given to children before age 5.
- **Short stature** (being shorter than normal).
- **Scoliosis** (curving of the spine) or **kyphosis** (rounding of the spine).
- One arm or leg is shorter than the other arm or leg.
- **Osteoporosis** (weak or thin bones that can break easily).
- **Osteoradionecrosis** (parts of the jaw bone die from a lack of blood flow).
- **Osteochondroma** (a benign tumor of the bone).

**Surgery**

Amputation or **limb-sparing surgery** to remove the cancer and prevent it from coming back may cause late effects depending on where the tumor was, age of the patient, and type of surgery. Health problems after amputation or limb-sparing surgery may include:

- Having problems with **activities of daily living**.
- Not being able to be as active as normal.
- **Chronic pain** or **infection**.
- Problems with the way **prosthetics** fit or work.
- Broken bone.
- The bone may not heal well after surgery.
- One arm or leg is shorter than the other.

Studies show no difference in **quality of life** in childhood cancer **survivors** who had amputation compared to those who had limb-sparing surgery.

**Chemotherapy and other drug therapy**

Risk may be increased in childhood cancer survivors who receive **anticancer therapy** that includes **methotrexate** or **corticosteroids** or **glucocorticoids** such as **dexamethasone**. **Drug therapy** may cause any of the following:

- **Osteoporosis** (weak or thin bones that can break easily).
• **Osteonecrosis** (one or more parts of a bone die from a lack of blood flow), especially in the hip or knee.

**Stem cell transplant**

A stem cell transplant can affect the bone and joints in different ways:

• **Total-body irradiation** (TBI) given as part of a stem cell transplant may affect the body's ability to make growth hormone and cause short stature (being shorter than normal). It may also cause osteoporosis (weak or thin bones that can break easily).
• **Osteochondroma** (a benign tumor of the long bones, such as the arm or leg bones) may form.
• **Chronic graft-versus-host disease** may occur after a stem cell transplant and cause joint contractures (tightening of the muscles that causes the joint to shorten and become very stiff). It may also cause osteonecrosis (one or more parts of a bone die from a lack of blood flow).

**Possible signs and symptoms of bone and joint late effects include swelling over a bone or bone and joint pain.**

These and other signs and symptoms may be caused by bone and joint late effects or by other conditions:

• Swelling over a bone or bony part of the body.
• Pain in a bone or joint.
• Redness or warmth over a bone or joint.
• Joint stiffness or trouble moving normally.
• A bone that breaks for no known reason or breaks easily.
• Short stature (being shorter than normal).
• One side of the body looks higher than the other side or the body tilts to one side.
• Always sitting or standing in a slouching position or having the appearance of a hunched back.

Talk to your child's doctor if your child has any of these problems.

**Certain tests and procedures are used to diagnose health problems in the bone and joint.**

These and other tests and procedures may be used to detect or diagnose bone and joint late effects:

• **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits, past illnesses and treatments will also be taken. An exam of the bones and muscles by a specialist may also be done.
• **Bone mineral density scan**: An imaging test that measures bone density (the amount of bone mineral in a certain amount of bone) by passing x-rays with two different energy levels through the bone. It is used to diagnose osteoporosis (weak or thin bones that can break easily).
Also called BMD scan, DEXA, DEXA scan, dual energy x-ray absorptiometric scan, dual x-ray absorptiometry, and DXA.

- **X-ray**: An x-ray is a type of energy beam that can go through the body and onto film, making a picture of areas inside the body, such as bones.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of bone and joint late effects. If tests are needed, find out how often they should be done.

### Reproductive System

#### Testicles

Testicular late effects are more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause testicular late effects:

- Acute lymphoblastic leukemia (ALL).
- Germ cell tumors.
- Hodgkin lymphoma.
- Non-Hodgkin lymphoma.
- Sarcoma.
- Testicular cancer.
- Cancers treated with total-body irradiation (TBI) before a stem cell transplant.

**Surgery, radiation therapy, and certain types of chemotherapy increase the risk of late effects that affect the testicles.**

The risk of health problems that affect the testicles increases after treatment with one or more of the following:

- Surgery, such as the removal of a testicle, part of the prostate, or lymph nodes in the abdomen.
- Chemotherapy with alkylating agents, such as cyclophosphamide, dacarbazine, procarbazine, and ifosfamide.
- Radiation therapy to the abdomen, pelvis, or in the area of the hypothalamus in the brain.
- Total-body irradiation (TBI) before a stem cell transplant.

**Late effects that affect the testicles may cause certain health problems.**

Late effects of the testicles and related health problems include the following:

- Low sperm count: A zero sperm count or a low sperm count may be temporary or permanent. This depends on the radiation dose and schedule, the area of the body treated, and the age when treated.
- Infertility: The inability to father a child.
- Retrograde ejaculation: Very little or no semen comes out of the penis during orgasm.
After treatment with chemotherapy or radiation, the body’s ability to make sperm may come back over time.

Ovaries

Ovarian late effects are more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause ovarian late effects:

- Acute lymphoblastic leukemia (ALL).
- Germ cell tumors.
- Hodgkin lymphoma.
- Ovarian cancer.
- Wilms tumor.
- Cancers treated with total-body irradiation (TBI) before a stem cell transplant.

Radiation therapy to the abdomen and certain types of chemotherapy increase the risk of ovarian late effects.

The risk of ovarian late effects may be increased after treatment with any of the following:

- Surgery to remove one or both ovaries.
- Chemotherapy with alkylating agents, such as cyclophosphamide, mechlorethamine, cisplatin, ifosfamide, lomustine, busulfan, and especially procarbazine.
- Radiation therapy to the abdomen, pelvis, or lower back. In survivors who had radiation to the abdomen, the damage to the ovaries depends on the radiation dose, age at the time of treatment, and whether all or part of the abdomen received radiation.
- Radiation therapy to the abdomen or pelvis together with alkylating agents.
- Radiation therapy to the area near the hypothalamus in the brain.
- Total-body irradiation (TBI) before a stem cell transplant.

Late effects that affect the ovaries may cause certain health problems.

Ovarian late effects and other health related problems include the following:

- Early menopause, especially in women who had their ovaries removed or were treated with both an alkylating agent and radiation therapy to the abdomen.
- Changes in menstrual periods.
- Infertility (inability to conceive a child).
- Puberty does not begin.

After treatment with chemotherapy, the ovaries may begin to work over time.
Possible signs and symptoms of ovarian late effects include irregular or absent menstrual periods and hot flashes.

These and other signs and symptoms may be caused by ovarian late effects or by other conditions:

- Irregular or no menstrual periods.
- **Hot flashes.**
- Drenching night sweats.
- Trouble sleeping.
- Mood changes.
- Lowered **sex drive.**
- Vaginal dryness.
- Inability to conceive a child.
- Sex traits, such as developing arm, pubic, and leg hair or having the **breasts** enlarge, do not occur at puberty.
- **Osteoporosis** (weak or thin bones that can break easily).

Talk to your child's doctor if your child has any of these problems.

**Fertility and reproduction**

**Treatment for cancer may cause infertility in childhood cancer survivors.**

The risk of infertility increases after treatment with the following:

- In boys, treatment with radiation therapy to the testicles.
- In girls, treatment with radiation therapy to the pelvis, including the ovaries and **uterus.**
- Radiation therapy to an area near the hypothalamus in the brain or lower back.
- Total-body irradiation (TBI) before a stem cell transplant.
- Chemotherapy with alkylation agents, such as cisplatin, cyclophosphamide, busulfan, lomustine, and procarbazine.
- Surgery, such as the removal of a testicle or an ovary or lymph nodes in the abdomen.

**Childhood cancer survivors may have late effects that affect pregnancy.**

Late effects on **pregnancy** include increased risk of the following:

- **High blood pressure.**
- **Diabetes** during pregnancy.
- **Anemia.**
- Miscarriage or stillbirth.
- Low birth-weight babies.
- Early labor and/or delivery.
- Delivery by Cesarean section.
- The fetus is not in the right position for birth (for example, the foot or buttock is in position to come out before the head).

Some studies have not shown an increased risk of late effects on pregnancy.

**There are methods that may be used to help childhood cancer survivors have children.**

The following methods may be used so that childhood cancer survivors can have children:

- Freezing the eggs or sperm before cancer treatment in patients who have reached puberty.
- Testicular sperm extraction (the removal of a small amount of tissue containing sperm from the testicle).
- Intracytoplasmic sperm injection (an egg is fertilized with one sperm that is injected into the egg outside the body).
- In vitro fertilization (IVF) (eggs and sperm are placed together in a container, giving the sperm the chance to enter an egg).

Children of childhood cancer survivors are not affected by the parent’s previous treatment for cancer.

The children of childhood cancer survivors do not appear to have an increased risk of birth defects, genetic disease, or cancer.

**Respiratory System**

**Lung late effects are more likely to occur after treatment for certain childhood cancers.**

Treatment for these and other childhood cancers may cause lung late effects:

- Hodgkin lymphoma.
- Wilms tumor.
- Cancers treated with a stem cell transplant.

**Certain types of chemotherapy and radiation to the lungs increase the risk of lung late effects.**

The risk of health problems that affect the lungs increases after treatment with the following:

- Surgery to remove all or part of the lung or chest wall.
- Chemotherapy. In survivors treated with chemotherapy, such as bleomycin, busulfan, carmustine, or lomustine, and radiation therapy to the chest, there is a high risk of lung damage.
- Radiation therapy to the chest. In survivors who had radiation to the chest, the damage to the lungs and chest wall depends on the radiation dose, whether all or part of the lungs and chest wall
received radiation, whether the radiation was given in small, divided daily doses, and the child's age at treatment.

- **Total-body irradiation** (TBI) or certain types of chemotherapy before a stem cell transplant.

The risk of lung late effects is greater in childhood cancer survivors who are treated with a combination of surgery, chemotherapy, and/or radiation therapy. The risk is also increased in survivors who have a history of the following:

- Infections or graft-versus-host disease after a stem cell transplant.
- Lung or airway disease, such as asthma, before cancer treatment.
- An abnormal chest wall.
- Smoking cigarettes or other substances.

**Late effects that affect the lungs may cause certain health problems.**

Lung late effects and related health problems include the following:

- Radiation pneumonitis (inflamed lung caused by radiation therapy).
- Pulmonary fibrosis (the build-up of scar tissue in the lung).
- Other lung and airway problems such as chronic obstructive pulmonary disease (COPD), pneumonia, cough that does not go away, and asthma.

**Possible signs and symptoms of lung late effects include trouble breathing and cough.**

These and other signs and symptoms may be caused by lung late effects or by other conditions:

- Dyspnea (shortness of breath), especially when being active.
- Wheezing.
- Fever.
- Chronic cough.
- Congestion (a feeling of fullness in the lungs from extra mucus).
- Chronic lung infections.
- Feeling tired.

Talk to your child's doctor if your child has any of these problems.

Lung late effects in childhood cancer survivors may occur slowly over time or there may be no symptoms. Sometimes lung damage can be detected only by imaging or pulmonary function testing. Lung late effects may improve over time.

**Certain tests and procedures are used to diagnose health problems in the lung.**

These and other tests and procedures may be used to detect or diagnose lung late effects:

- **Physical exam and health history:** An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Chest x-ray**: An x-ray of the organs and bones inside the chest. An x-ray is a type of energy beam that can go through the body and onto film, making a picture of areas inside the body.

- **Pulmonary function test (PFT)**: A test to see how well the lungs are working. It measures how much air the lungs can hold and how quickly air moves into and out of the lungs. It also measures how much oxygen is used and how much carbon dioxide is given off during breathing. This is also called lung function test.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of lung late effects. If tests are needed, find out how often they should be done.

**Health habits that promote healthy lungs are important for survivors of childhood cancer.**

Childhood cancer survivors with lung late effects should take care to protect their health, including:

- Not smoking.
- Getting vaccines for flu and pneumococcus.

**Senses**

**Hearing**

Hearing problems are a late effect that is more likely to occur after treatment for certain childhood cancers.

Treatment for these and other childhood cancers may cause hearing late effects:

- Brain tumors.
- Head and neck cancers.
- Neuroblastoma.
- Retinoblastoma.
- Liver cancer.
- Germ cell tumors.
- Bone cancer.
- Soft tissue sarcoma.

**Radiation therapy to the brain and certain types of chemotherapy increase the risk of hearing loss.**

The risk of hearing loss is increased in childhood cancer survivors after treatment with the following:

- Certain types of chemotherapy, such as cisplatin or high-dose carboplatin.
- Radiation therapy to the brain.
The risk of hearing loss is greater in childhood cancer survivors who were young at the time of treatment (the younger the child, the greater the risk), were treated for a brain tumor, or received radiation therapy to the brain and chemotherapy at the same time.

**Hearing loss is the most common sign of hearing late effects.**

These and other signs and symptoms may be caused by hearing late effects or by other conditions:
- Hearing loss.
- Ringing in the ears.
- Feeling dizzy.
- Too much hardened wax in the ear.

Hearing loss may occur during treatment, soon after treatment ends, or several months or years after treatment ends and worsen over time. Talk to your child's doctor if your child has any of these problems.

**Certain tests and procedures are used to diagnose health problems in the ear and hearing problems.**

These and other tests and procedures may be used to detect or diagnose hearing late effects:
- **Physical exam and health history:** An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Otoscopic exam:** An exam of the ear. An otoscope is used to look at the ear canal and the eardrum to check for signs of infection or hearing loss. Sometimes the otoscope has a plastic bulb that is squeezed to release a small puff air into the ear canal. In a healthy ear, the eardrum will move. If there is fluid behind the eardrum, it will not move.
- **Hearing test:** A hearing test can be done in different ways depending on the child's age. The test is done to check if the child can hear soft and loud sounds and low- and high-pitched sounds. Each ear is checked separately. The child may also be asked if he or she can hear the high-pitched hum of a tuning fork when it is placed behind the ear or on the forehead.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of hearing late effects. If tests are needed, find out how often they should be done.

**Seeing**

**Eye and vision problems are a late effect that is more likely to occur after treatment for certain childhood cancers.**

Treatment for these and other childhood cancers may cause eye and vision late effects:
- Retinoblastoma, rhabdomyosarcoma, and other tumors of the eye.
- Brain tumors.
- Head and neck cancers.
- Acute lymphoblastic leukemia (ALL).
- Cancers treated with total-body irradiation (TBI) before a stem cell transplant.

**Radiation therapy to the brain or head increases the risk of eye problems or vision loss.**

The risk of eye problems or vision loss may be increased in childhood cancer survivors after treatment with any of the following:

- Radiation therapy to the brain, eye, or eye socket.
- Surgery to remove the eye or a tumor near the optic nerve.
- Certain types of chemotherapy, such as cytarabine and doxorubicin or busulfan and corticosteroids as part of a stem cell transplant.
- Total-body irradiation (TBI) as part of a stem cell transplant.
- Stem cell transplant (and a history of chronic graft-versus-host disease).

**Late effects that affect the eye may cause certain health problems.**

Eye late effects and related health problems include the following:

- Having a small eye socket that affects the shape of the child’s face as it grows.
- Loss of vision.
- Vision problems, such as cataracts or glaucoma.
- Not being able to make tears.
- Damage to the optic nerve and retina.
- Eyelid tumors.

**Possible signs and symptoms of eye and vision late effects include changes in vision and dry eyes.**

These and other signs and symptoms may be caused by eye and vision late effects or by other conditions:

- Changes in vision, such as:
  - Not being able to see objects that are close.
  - Not being able to see objects that are far away.
  - Double vision.
  - Cloudy or blurred vision.
  - Colors seem faded.
  - Being sensitive to light or trouble seeing at night.
  - Seeing a glare or halo around lights at night.
- Dry eyes that may feel like they are itchy, burning, or swollen, or like there is something in the eye.
- Eye pain.
● Eye redness.
● Having a growth on the eyelid.
● Drooping of the upper eyelid.

Talk to your child's doctor if your child has any of these problems.

**Certain tests and procedures are used to diagnose health problems in the eye and vision problems.**

These and other tests and procedures may be used to detect or diagnose eye and vision late effects:

- **Eye exam with dilated pupil:** An exam of the eye in which the pupil is dilated (widened) with medicated eye drops to allow the doctor to look through the lens and pupil to the retina. The inside of the eye, including the retina and the optic nerve, is checked using an instrument that makes a narrow beam of light. This is sometimes called a slit-lamp exam. If there is a tumor, the doctor may take pictures over time to keep track of changes in the size of the tumor and how fast it is growing.
- **Indirect ophthalmoscopy:** An exam of the inside of the back of the eye using a small magnifying lens and a light.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of eye and vision late effects. If tests are needed, find out how often they should be done.

**Urinary System**

**Kidney**

**Certain types of chemotherapy increase the risk of kidney late effects.**

The risk of health problems that affect the kidney increases after treatment with the following:

- Chemotherapy including cisplatin, carboplatin, ifosfamide, and methotrexate.
- Radiation therapy to the abdomen or middle of the back.
- Surgery to remove part or all of a kidney.
- Stem cell transplant.

The risk of kidney late effects is greater in childhood cancer survivors who are treated with a combination of surgery, chemotherapy, and/or radiation therapy.

The following may also increase the risk of kidney late effects:

- Having cancer in both kidneys..
- Having a genetic syndrome that increases the risk of kidney problems, such as Denys-Drash syndrome or WAGR syndrome.
- Being treated with more than one type of treatment.

**Late effects that affect the kidney may cause certain health problems.**
Kidney late effects or related health problems include the following:

- Damage to the parts of the kidney that filter and clean the blood.
- Damage to the parts of the kidney that remove extra water from the blood.
- Loss of electrolytes, such as magnesium, calcium, or potassium, from the body.
- Hypertension (high blood pressure).

Possible signs and symptoms of kidney late effects include problems urinating and swelling of the feet or hands.

These and other signs and symptoms may be caused by kidney late effects or by other conditions:

- Feeling the need to urinate without being able to do so.
- Frequent urination (especially at night).
- Trouble urinating.
- Feeling very tired.
- Swelling of the legs, ankles, feet, face, or hands.
- Itchy skin.
- Nausea or vomiting.
- A metal-like taste in the mouth or bad breath.
- Headache.

Sometimes there are no signs or symptoms in the early stages. Signs or symptoms may appear as damage to the kidney continues over time. Talk to your child's doctor if your child has any of these problems.

Certain tests and procedures are used to diagnose health problems in the kidney.

These and other tests and procedures may be used to detect or diagnose kidney late effects:

- **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Blood chemistry study**: A procedure in which a blood sample is checked to measure the amounts of certain substances, such as magnesium, calcium, and potassium, released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance may be a sign of kidney disease.
- **Urinalysis**: A test to check the color of urine and its contents, such as sugar, protein, red blood cells, and white blood cells.
- **Ultrasound exam**: A procedure in which high-energy sound waves (ultrasound) are bounced off internal tissues or organs, such as the kidney, and make echoes. The echoes form a picture of body tissues called a sonogram. The picture can be printed to be looked at later.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of kidney late effects. If tests are needed, find out how often they should be done.
Health habits that promote healthy kidneys are important for survivors of childhood cancer.

Childhood cancer survivors who had all or part of their kidney removed should talk to their doctor about the following:

- Whether it is safe to play sports that have a high risk of heavy contact or impact such as football or hockey.
- Bicycle safety and avoiding handlebar injuries.
- Wearing a seatbelt around the hips, not the waist.

**Bladder**

Surgery to the pelvic area and certain types of chemotherapy increase the risk of bladder late effects.

The risk of health problems that affect the bladder increases after treatment with the following:

- Surgery to remove all or part of the bladder.
- Surgery to the pelvis, spine, or brain.
- Certain types of chemotherapy, such as cyclophosphamide or ifosfamide.
- Radiation therapy to areas near the bladder, pelvis, or urinary tract.
- Stem cell transplant.

Late effects that affect the bladder may cause certain health problems.

Bladder late effects and related health problems include the following:

- Hemorrhagic cystitis (inflammation of the inside of the bladder wall, which leads to bleeding).
- Thickening of the bladder wall.
- Trouble emptying the bladder.
- Incontinence.
- A blockage in the kidney, ureter, bladder, or urethra.
- Urinary tract infection (chronic).

Possible signs and symptoms of bladder late effects include changes in urination and swelling of the feet or hands.

These and other signs and symptoms may be caused by bladder late effects or by other conditions:

- Feeling the need to urinate without being able to do so.
- Frequent urination (especially at night).
- Trouble urinating.
- Feeling like the bladder does not empty completely after urination.
● Swelling of the legs, ankles, feet, face, or hands.
● Little or no bladder control.
● Blood in the urine.

Talk to your child's doctor if your child has any of these problems.

Certain tests and procedures are used to diagnose health problems in the bladder.

These and other tests and procedures may be used to detect or diagnose bladder late effects:

● **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.

● **Blood chemistry study**: A procedure in which a blood sample is checked to measure the amounts of certain substances, such as magnesium, calcium, and potassium, released into the blood by organs and tissues in the body. An unusual (higher or lower than normal) amount of a substance may be a sign of bladder problems.

● **Urinalysis**: A test to check the color of urine and its contents, such as sugar, protein, red blood cells, and white blood cells.

● **Urine culture**: A test to check for bacteria, yeast, or other microorganisms in the urine when there are symptoms of infection. Urine cultures can help identify the type of microorganism that is causing an infection. Treatment of the infection depends on the type of microorganism that is causing the infection.

● **Ultrasound exam**: A procedure in which high-energy sound waves (ultrasound) are bounced off internal tissues or organs, such as the bladder, and make echoes. The echoes form a picture of body tissues called a sonogram. The picture can be printed to be looked at later.

Talk to your child's doctor about whether your child needs to have tests and procedures to check for signs of bladder late effects. If tests are needed, find out how often they should be done.
Tips for Coping with the Fear of Recurrence

**Some of the information in this section has been adapted from Cancer.Net, and it is available in its entirety at:** [https://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence](https://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence)

Living with uncertainty is never easy. It is important to remind yourself that fear and anxiety are normal parts of survivorship. Worrying about cancer coming back is usually most intense in the first year after treatment. This worry usually gets better over time.

Here are a few ideas to help you cope with the fear of recurrence:

- **Recognize your emotions.** Many people try to hide or ignore “negative” feelings like fear and anxiety. Ignoring them only allows them to become stronger and more overwhelming. It often helps to talk about your fears with a trusted friend, family member, or mental health professional. Talking out loud about your concerns may help you figure out the reasons behind your fears. This might include the fear of having to repeat cancer treatment, losing control over your life, or facing death. You can also try writing down your thoughts.

- **Don't ignore your fears.** Telling yourself not to worry or criticizing yourself for being afraid will not make these feelings go away. Accept that you are going to experience some fear, and focus on ways to manage the **anxiety**. Be aware that your anxiety may temporarily increase at specific times. These may include follow-up care appointments, the anniversary of your diagnosis, or someone else’s cancer diagnosis. Sometimes, what you are worrying about may be unlikely. Talking to your health care team may help you figure out if your fears are likely.

- **Do not worry alone.** Many cancer survivors find joining a support group to be helpful. Support groups offer the chance to share feelings and fears with others who understand. They also allow you to exchange practical information and helpful suggestions. The group experience often creates a sense of belonging that helps survivors feel less alone and more understood.

- **Reduce stress.** Finding ways to **manage stress** will help lower your overall level of anxiety. Try different ways of reducing stress to find out what works best for you. This could include:
- Spending time with family and friends
- Focusing on hobbies and other activities you enjoy
- Taking a walk, meditating, or enjoying a bath
- Exercising regularly
- Reading a funny book or watching a funny movie

- **Be well informed.** Most cancers have a predictable pattern of recurrence. But no one can tell you exactly what will happen in the future. A health care professional who knows your medical history can tell you about the chances of the cancer returning. He or she can also tell you what symptoms to look for. Knowing what to expect may help you stop worrying that every ache or pain means the cancer has returned. If you do experience a symptom that does not go away or gets worse, talk with your health care team.

- **Talk with your health care team about follow-up care.** One goal of follow-up care is to check for a recurrence of cancer. Your follow-up care plan may include regular physical examinations and/or medical tests to keep track of your recovery. Having a regular schedule of follow-up visits can provide survivors with a sense of control. Find more information on [developing a survivorship care plan](#).

- **Make healthy choices.** Healthy habits like eating nutritious meals, exercising regularly, and getting enough sleep help people feel better both physically and emotionally. Avoiding unhealthy habits, like smoking and excessive drinking, helps people feel like they have more control over their health. Read more about [healthy living after cancer](#).

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**When You Need More Help**

You might find yourself overwhelmed by fear or anxiety even after your best efforts to cope with it. The following feelings may indicate more serious anxiety or depression:

- Worry or anxiety that gets in the way of your relationships and daily activities or prevents you from going to your follow-up care appointments
- Feeling hopeless about the future
- Having trouble sleeping or eating well
- Not participating in activities you used to enjoy
- Having trouble concentrating or making decisions
- Feeling that you have nothing to look forward to
- Being unusually forgetful

If you are concerned about anything on this list, talk with your health care team. You may also want to consider [counseling](#).
Additional Resources/Readings:


**SURVIVORSHIP RESOURCES AND INFORMATION**

**Please visit the new “Neuroblastoma Survivorship Database” on the NCCS website for an extensive list of topics and resources to address neuroblastoma survivorship topics!**

**The Hope Portal is the best resource that we recommend repeatedly! It is run by the Coalition Against Childhood Cancer (CAC2), “a membership organization (around 100 childhood cancer organizations and more than 50 individuals who care greatly about childhood cancer). They are organized around three basic pillars of interest that our members share: Research and Treatment, Family Support and Survivorship, and Awareness and Advocacy, and we work to share information with and among our members to and provide numerous opportunities for education within each pillar. They also promote coordinated action and broad based-collaboration.” The Neuroblastoma Children’s Cancer Society (NCCS) is a proud and active member of the Coalition Against Childhood Cancer!**

“The Hope Portal, www.hope-portal.org, is a searchable database that allows childhood cancer families and healthcare professionals across the country to find support faster with less effort and in a more personalized way than ever. Users can search the Hope Portal by specifying diagnosis, geographic location, and type of assistance needed. Whether families are looking for financial support, comfort items, camp opportunities, or just someone to talk to, the Hope Portal is one-stop to help meet families’ needs.”
General Survivorship Resources and Information


  “As you finish cancer treatment, you might be wondering: What happens next? The answer is different for every person. Some people return to the lives they were leading before their diagnosis, while the lives of others are significantly changed by their cancer experience. The challenge for every survivor is figuring out how to return to everyday life while adjusting to the effects of the disease and its treatment.”


- “After Treatment – Living as a Childhood Neuroblastoma Cancer Survivor” - https://www.acco.org/blog/after-treatment-living-as-a-childhood-neuroblastoma-cancer-survivor/


- Survivor Care - https://www.pogo.ca/programs-support/survivor-care/

- “NCI Office of Cancer Survivorship” - https://cancercontrol.cancer.gov/ocs The NCI Office of Cancer Survivorship (OCS) works to enhance the quality and length of survival of all persons diagnosed with cancer and to prevent, minimize, or manage adverse effects of cancer and its treatment.

- “Cancer Survivorship: Addressing Complex Needs Throughout the Lifespan” - https://www.cancer.gov/research/annual-plan/scientific-topics/survivorship

- “Livestrong Foundation” - https://www.livestrong.org/

  Through the Lance Armstrong Foundation's online education resource at www.LIVESTRONG.org/CancerSupport, cancer survivors can learn about their cancer-related concerns, such as the physical and emotional effects of cancer and its treatment and managing day-to-day matters. In addition, survivors can download worksheets to organize and guide their cancer experiences and hear stories shared by other cancer survivors.

- “The National Coalition for Cancer Survivorship” - https://canceradvocacy.org/ OR 877-NCCS-YES
This is the oldest survivor-led cancer advocacy organization in the country and a highly respected authentic voice at the federal level, advocating for quality cancer care for all Americans and empowering cancer survivors.

- **Cancer Survival Toolbox** - [https://canceradvocacy.org/resources/cancer-survival-toolbox/](https://canceradvocacy.org/resources/cancer-survival-toolbox/)
- **Resource information about Integrative, Complementary and Alternative Medicine (CAM) cancer treatments** - [https://www.aosw.org/AOSW/media/Main-Site-Files/People%20Affected%20by%20Cancer/Documents/CAMResources-(3).pdf](https://www.aosw.org/AOSW/media/Main-Site-Files/People%20Affected%20by%20Cancer/Documents/CAMResources-(3).pdf)
- **“CancerCare”** – [https://www.cancercare.org/](https://www.cancercare.org/)
  - **“Post-Treatment Survivorship”** - [https://www.cancercare.org/tagged/post-treatment_survivorship](https://www.cancercare.org/tagged/post-treatment_survivorship)
- **Services:**
  - **Case Management** – “Our staff of professional oncology social workers provide case management services to help you better cope with cancer.” (In U.S. and Puerto Rico)
  - **Support Groups** – online and live
  - **“Connect Education Workshops: Post-Treatment Survivorship”** (many different topics) - [https://www.cancercare.org/connect_workshops#!past_workshops](https://www.cancercare.org/connect_workshops#!past_workshops)
  - **“Publications – General Topics: Post-Treatment Survivorship”** (many different topics) - [https://www.cancercare.org/publications#!general_topics](https://www.cancercare.org/publications#!general_topics)
  - **Limited Financial Assistance**
  - **“Ask Cancer Care”** (submit a question and get an answer from an expert on a particular topic) - [https://www.cancercare.org/questions](https://www.cancercare.org/questions)

**Survivor Clinics**

- **“Long-Term Follow Up Clinics”** - [https://www.thenccs.org/long-term-clinics/](https://www.thenccs.org/long-term-clinics/)
- **“Cancer Survivor Link”** - [https://www.cancersurvivorlink.org/](https://www.cancersurvivorlink.org/)
  
  
  - **Find a Survivor Clinic** - [https://www.cancersurvivorlink.org/Clinics.aspx](https://www.cancersurvivorlink.org/Clinics.aspx)


**Survivorship Care Plans**


**Survivorship Guidelines, Studies**

- “Survivorship: During and After Treatment” - http://m.cancer.org/treatment/survivorshipduringandaftertreatment/index  (Multiple links for survivorship are available on this page.)
- “Neuroblastoma, Childhood Cancer Survivorship, and Reducing the Consequences of Cure” - http://www.nature.com/bmt/journal/v40/n8/full/1705815a.html
- “Neuroblastoma - Childhood - Survivorship: Cancer.Net” - www.cancer.net/cancer-types/neuroblastoma-childhood/survivorship  (At the end of the write-up, there are multiple links for additional survivor resources available on Cancer.net.)
- “Childhood Cancer Survivor Study” - https://css.stjude.org/
- “ Childhood Cancer Survivor Study” - https://www.cancer.gov/types/childhood-cancers/css  (Late Effects)
- “St. Jude – Long-Term Follow-Up Study (LTFU)” - https://ltfu.stjude.org/
- “Clinical Guidelines for the Care of Childhood Cancer Survivors” - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4928728/
- “Guidelines on Survivorship Care” - https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship-compendium-0  (There are multiple links available on this website)

**Support/Support Groups**

- Cancer Survivors Network - https://csn.cancer.org/
- Cancer Care Network - https://www.cancercare.org/
- National Cancer Institute – Additional Support Organizations -  

- “StupidCancer” - https://stupidcancer.org/
  - Stupid Cancer offers a lifeline to the adolescent and young adult cancer community by connecting them to age-appropriate resources and peers who get it. Our mission is to empower adolescents and young adults affected by cancer by ending isolation and building community.”
  - Stupid Cancer Digital Meetups - Digital Meetups happen every Monday night at 9pm Eastern/ 6pm Pacific and Thursday night at 8pm Eastern/ 5pm Pacific, plus additional ones each week. Log on from the comfort of your own home (or laptop or phone)!
  - Stupid Cancer Stories – from various members of the community,

  “Ped-onc-survivors was founded in September of 2000 by a parent of a survivor of an adolescent cancer and a long term survivor of an adolescent cancer. POS is intended for parents/family members of survivors who are off treatment for any type of childhood cancer. In POS, we discuss all aspects of survivorship, and share ideas, information, and support.”

  “N-blastoma is an e-mail support list for parents and caregivers of children who have had a diagnosis of neuroblastoma. All aspects of treatment and emotional support issues are discussed.


- “Childhood Cancer International” – https://www.childhoodcancerinternational.org/
  - Includes links for international childhood cancer survivorship groups from a variety of countries
  - Includes a handbook for creating and sustaining a survivor group

- Smart Patients – https://www.smartpatients.com/
  - “Smart Patients is an online community for patients and families affected by a variety of illnesses. Here you can learn at your own level about scientific developments related to your condition, share your questions and concerns with other members, and use what you learn in the context of your own life.”
General Financial Assistance, Grants, Scholarships


The SamFund - www.thesamfund.org

Cuck Fancer – https://www.cuckfancer.org/
Gives out Grants – “Cuck Fancer. will contribute anything necessary so young adult survivors can get their feet back on the ground: Rent, tuition, school supplies, car payments or medical bills, Cuck Fancer. strives to eliminate obstacles in any way possible so that young adult cancer survivors can move forward in their lives with a sense of purpose.”

Smile – https://www.smileasier.org/
“The SMILE Kids Program provides children impacted by a life-threatening condition with assistive and adaptive equipment that is cost prohibitive but will enhance their quality of life and ultimately making life a little easier...Each SMILE Kid's request is unique to their individual needs. With the help of volunteers and sponsors, SMILE takes care of ordering, purchasing, assembling, delivering, and installing each piece of equipment so that SMILE Kids and their families can focus on creating more SMILEs.”
- Examples: Hearing aids, specialized beds and strollers, wheelchair lifts, therapeutic tricycles, etc.

  “There are national and regional resources dedicated to improve access to quality care and decrease the financial burden of medical treatment, and we can help you locate them quickly and easily…To generate a list of the potential organizations that may have programs to address your needs, select the searching criteria that is the best match as it relates to the patient. There is no limit to the number of different searches you can perform.”
  “This independent division of Patient Advocate Foundation provides small grants to patients who meet financial and medical criteria. Grants are provided on a first-come first served basis and are distributed until funds are depleted. Qualifications and processes for each fund may differ based on fund requirements. Patients who are interested in applying for financial assistance should start by calling this
division toll free at (855) 824-7941 or by registering your account and submitting an application online.”

- Co-Pay Relief Program:
  “The PAF Co-Pay Relief Program, one of the self-contained divisions of PAF, provides direct financial assistance to insured patients who meet certain qualifications to help them pay for the prescriptions and/or treatments they need. This assistance helps patients afford the out-of-pocket costs for these items that their insurance companies require.”  Call Co-Pay Relief directly at 1-866-512-3861

Cancer Survivors’ Fund (provides prosthetic limbs) - [http://cancersurvivorsfund.org](http://cancersurvivorsfund.org)

HealthWell Foundation - [https://www.healthwellfoundation.org/patients/](https://www.healthwellfoundation.org/patients/)
  “When health insurance is not enough, we’re here to help — with copays, premiums, deductibles and out-of-pocket expenses for supplies, supplements, surgeries and more. We offer financial assistance through a number of Disease Funds, with new funds opening every year, so you can get the care you need.

  “UnitedHealthcare Children’s Foundation Grant” - [https://www.uhccf.org/apply-for-a-grant/what-is-a-uhccf-grant/](https://www.uhccf.org/apply-for-a-grant/what-is-a-uhccf-grant/)
  “UHCCF’s mission is to fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. UHCCF grants provide financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan.”

Children’s Health Insurance Plan - By state
[https://www.medicaid.gov/chip/index.html](https://www.medicaid.gov/chip/index.html)

*MDSAVE purchase individual tests for cheap

*Call insurance company for financial relief fund

**Hearing Aid Support**

Lions- Hearing Screening
Headquarters (Contact Information)
300 W. 22nd Street
Oak Brook IL 60523
630/571-8842
[www.lionsclub.org](http://www.lionsclub.org)

Starkey Foundation-free hearing aid (not quite sure if it is actually free or pay at sliding fee scale)
316/942-4221
[www.starkeyhearingfoundation.org](http://www.starkeyhearingfoundation.org)
American Medical Resources Foundation
P.O. Box 3609
Audient (Alliance for Accessible Hearing Care)
866/956-5400
http://www.audientalliance.org/patient/php

Better Hearing Institute
800/327-9355
“Your Guide To Financial Assistance for Hearing Aids” is available online at:
http://www.betterhearing.org/pdfs/e-Guides/Financial_Assistance_For_Hearing_Aids.pdf

CareCredit and Starkey SoundChoice
901 East Cerritos Avenue
Anaheim, CA 92805
800/839-9078
www.carecredit.com

Connecticut Tech Art Project
25 Sigourney Street, 11th floor
Hartford CT 06106
860/424-4881 (Voice)
860/424-4839 (TTY)
800/537-2549
www.cttechact.com

Community Service or Civil Organizations (Check online for your updated local organization contact)
• Civitan International: www.civitaninternational.com
• Kiwanis International: www.kiwanisct.com
• Pilot International: www.pilotinternational.org
• Quota International: www.quota.org
• Rotary International: www.rotary.org
• Sertoma International: www.sertoma.org

Disabled Children’s Relief Fund
P.O. Box 89
402 Pennsylvania Avenue
Freeport, NY 11520
516/377-1605
www.dcrf.com

Easter Seals Agencies
Over 400 local service centers with varying services; some assist low-income adults and children with hearing aids and other rehabilitative devices.

www.easterseals.com (find your location)

Foundation for Sight & Sound
The Foundation for Sight & Sound has partnered with EarQ Group to provide hearing aids to individuals with limited financial resources-Help America Hear (HAH) Program
P.O. Box 1245
Smihtown, NY 11787
631/366-3461
info@foundationforsightandsound.org (E-mail)
http://www.foundationforsightandsound.org/projects.html

The Hearing Impaired Kids Endowment Fund- The HIKE Fund, Inc.
10115 Cherryhill Place
Spring Hill, FL 34608
352/688-2578 (voice/FAX)
www.thehikefund.org

Hearing Loss Association of America
“Children with hearing loss might be able to receive hearing assistive technology at no cost if their Individualized Education Program (IEP) specifies they need the assistive technology (such as hearing aids or FM systems) in order to receive a Free and Appropriate Public Education (FAPE). For more information, see the Individuals with Disabilities Education Act (IDEA).”
6116 Executive Blvd, Suite 320
Rockville, MD 20852
301-657-2248
https://www.hearingloss.org/

Knights of Columbus
470 Washington Street, Suite #6
P.O. Box 194
Norwood, MA 02062
781/551-0628 (Voice)
781/551-0490 (FAX)
http://massachusettsstatekofc.org

Miracle Ear Children’s Foundation
P.O. Box 59261
Minneapolis, MN 55459
800/234-5422
763/268-4295 (FAX)
www.miracle-ear.com/childrenrequest.aspx
Military Audiology Association – RACHAP/RHAPP
http://miltaryaudiology.org/site/aids/

Local SHHH (Hearing Loss Association of America)
www.shhh.org

Travelers Protective Association of America Scholarship Trust for the Deaf and Near Deaf
3755 Lindell Boulevard
St. Louis, MO 63108-3476
314/371-0533 (Voice)
314/371-0537 (FAX)
http://www.tpahq.org/scholarshiptrust.html
**COLLEGE SCHOLARSHIPS**

- Cancer for College - [https://www.cancerforcollege.org/](https://www.cancerforcollege.org/)
  Available scholarships - [https://cancerforcollege.org/available-scholarships/](https://cancerforcollege.org/available-scholarships/)

- Cancer Survivors’ Fund - [http://cancersurvivorsfund.org](http://cancersurvivorsfund.org)
  - Scholarships - [http://cancersurvivorsfund.org/ScholarshipEligibilityRequirements.htm](http://cancersurvivorsfund.org/ScholarshipEligibilityRequirements.htm)

- “25 Great Scholarships for Cancer Survivors” - [https://www.top10onlinecolleges.org/scholarships-for/cancer-survivors/](https://www.top10onlinecolleges.org/scholarships-for/cancer-survivors/)

- “Scholarships for Cancer Survivors and Patients” - [http://www.collegescholarships.org/scholarships/cancer-students.htm](http://www.collegescholarships.org/scholarships/cancer-students.htm)

- “College Scholarships” - [http://www.ped-onc.org/scholarships/](http://www.ped-onc.org/scholarships/)

- Kids 4 Kids with Cancer - [http://www.kids4kidswithcancer.org/scholarships](http://www.kids4kidswithcancer.org/scholarships)

- “College Scholarships” - [https://www.thenccs.org/scholarship/](https://www.thenccs.org/scholarship/)


- “Education Scholarships” - [https://www.acco.org/education-scholarships/](https://www.acco.org/education-scholarships/)

- “The Ulman Foundation – Scholarships” - [https://ulmanfoundation.org/scholarships/](https://ulmanfoundation.org/scholarships/)

- SurvivorVision – [https://www.survivorvision.org/](https://www.survivorvision.org/)
  - Provides scholarships for textbooks
  - “To provide a network of support to survivors of pediatric cancer through: advocacy and support groups in the community, funding to support research initiatives, educational programs and resources to enhance a survivors’ quality of life while minimizing cancers long term effects.”

**Other Organizations Offering Scholarships:**

Addi’s Faith Foundation - [https://addisfaithfoundation.org/what-we-do/scholarships/](https://addisfaithfoundation.org/what-we-do/scholarships/)

Friends of Scott - [https://www.friendsofscott.org/scholarship.aspx](https://www.friendsofscott.org/scholarship.aspx)

Jack’s Ride Scholarship Program - [http://www.jacksride.org/scholarship.html](http://www.jacksride.org/scholarship.html)
National Collegiate Cancer Foundation - http://collegiatecancer.org/scholarships/ 

- Survivor Scholarship Program 
- Sibling Scholarship Program 

The Simon Cancer Foundation Scholarship Program - http://www.thescf.org/Scholarships.html 

Snowdrop Foundation - http://snowdropfoundation.org/our-cause/snowdrop-scholarship-program/ 

The Pediatric Brain Tumor Foundation - http://www.curethekids.org/family-resources/scholarships/ 

The SAMFund for Young Adult Survivors of Cancer - http://www.thesamfund.org/get-help/grants/ 

The Ulman Cancer Fund for Young Adults - Scholarships - Young Adults Impacted By Cancer | Ulman Foundation 

Internship: 

FDA summer internship for survivors and siblings - https://www.fda.gov/about-fda/scientific-internships-fellowships-trainees-and-non-us-citizens/oce-summer-scholars-program
SEPTEMBER AWARENESS AND ADVOCACY

September – Childhood Cancer Awareness Month

September has been dedicated as Childhood Cancer Awareness Month, in an effort to bring recognition to the children, families, and survivors affected by childhood cancer. Childhood cancer is the leading cause of death by disease among children, and awareness is important to bring in additional funding to find cures for all types of childhood cancers and better treatments so that survivors live longer and better lives. All childhood and adolescent cancers are represented by a GOLD awareness ribbon. Gold was chosen because it is a precious metal, and nothing is more precious than children.

1. Bold and Turn Your Social Media Gold!
   A. Follow Childhood Cancer Facebook pages for easily shareable content
      i. https://www.facebook.com/CoalitionAgainstChildhoodCancer
      ii. https://www.facebook.com/MakeSeptemberGold/
      iii. https://www.facebook.com/americanchildhoodcancer/
      v. https://www.facebook.com/OAFcarepackages/
   B. “I Draw Childhood Cancer” – A mom whose child was diagnosed with cancer turned to drawing to childhood cancer and the various procedures that are involved, in an effort to help her daughters and others. https://www.facebook.com/idrawchildhoodcancer/
   C. Go Gold with Photo Frames
      Instructions on How to Add a Frame to Your Facebook Profile Photo - https://www.facebook.com/help/115229555800383

2. Do Something!
   A. Get your friends to be a donor!
      i. Bone Marrow - https://bethematch.org/

3. Fundraise for Research
   A. Worthy Research Causes
      i. The Neuroblastoma Children’s Cancer Society (NCCS) gives the majority of its donations to research - https://www.neuroblastomacancer.org/ or https://www.facebook.com/NeuroblastomaChildrensCancerSociety
      ii. https://research.beatcc.org/ (Formerly Beat Neuroblastoma)
      iii. https://www.bandofparents.org/
      iv. https://www.solvingkidscancer.org/
      v. https://www.alexslemonade.org/
   B. Facebook Fundraisers
Facebook has both Birthday fundraisers and Giving Tuesday (held annually the Tuesday after Thanksgiving) to raise money for nonprofit organizations, and NCCS is one of the nonprofits that you can select! If you have any questions or need assistance setting either of these up, please feel free to contact us!

**YouTube Instructions for Creating a Facebook fundraiser**
https://www.youtube.com/watch?v=wGOyV368G1Y

### C. Other Creative Fundraising Options

1. **Amazon Smile** – when you shop with this link, a percentage is donated to neuroblastoma research at no extra cost to you: smile.amazon.com/ch/36-3969321
2. **Alex’s Million Mile** - Running/ Walking for a cure
   https://www.alexslemonade.org/campaign/the-million-mile-2020
3. **PJammin’ For Kids with Cancer** - Host a pajama day at your work or school
   https://www.acco.org/pjammin/

### 4. Create and sell...

**A. Awareness ribbons to share- get them free here**
https://www.facebook.com/ShowMeYourGold365

**B. T-shirts** – Below are several companies that you could utilize:
- **Bonfire** - https://www.bonfire.com/sell-online/
  From the Article, “Sell Merchandise for Your Nonprofit Without Dealing with Inventory” - https://smartcausedigital.com/articles/sell-merchandise-your-nonprofit-without-dealing-inventory, Lists the Following Companies:
  - **CaféPress** - https://www.cafepress.com/
  - **Printfection** - https://www.printfection.com/
  - **Spreadshirt** - https://www.spreadshirt.com/
  - **Zazzle** - https://www.zazzle.com/

**C. Wristbands** - https://wristbandcreation.com/ (“Find a lower price and we will beat it”)

**D. Bumper stickers/Decals** -
- **CaféPress** - https://www.cafepress.com/
- **Oriental Trading** - https://www.orientaltrading.com/personalized-awareness-ribbon-car-magnets-a2-13704774.fltr?categoryId=90000%201969&rd=Childhood%20cancer&fbclid=IwAR2adKfaPXCxtcOKXrkEMexO6scjtzKcSug0lqBXpOFIm6gnWDDOi7xNDI
  - **Zazzle** - https://www.zazzle.com/

**E. Yard Signs/Posters** – Check Pinterest and Google images for many different ideas! Or, you could visit your local print shop to get a professionally printed sign, or visit the following online companies to create posters and yard signs:
- **CaféPress** - https://www.cafepress.com/
- **VistaPrint** - https://www.vistaprint.com/

**F. Awareness Ribbons and Decorative Hangings for Mailbox, Front Door, or Yard** - Check Pinterest and Google images for many different ideas and options to create your own. Or, you can visit Etsy to purchase one.

### 5. Get Involved with Social Policy

1. Sign an e-petition for federal funding and research
2. Contact, email or tweet your congressional representatives
3. Post about childhood cancer advocacy efforts on social media outlets (Twitter, Facebook, blogs, etc.)

Additional Awareness Tools and Pages
- https://rallyfoundation.org/awareness-tools/
- https://curechildhoodcancer.org/childhood-cancer-awareness-month/?gelid=Cj0KCQjw753rBRCVARIsANe3o478O8f18pxf50p056_zbS-S4ixdkAkNePCD0006HNXqI9iFcWLLFm8aAhBfEAlw_wcB
- The Coalition Against Childhood Cancer (CAC2) puts out facts, statistics, etc. on Facebook during the month of September on their public Facebook page. However, you can access MANY different facts, statistics, etc. all in one place about childhood cancer, which are updated on a yearly basis. The Childhood Cancer Fact Library is located at: https://cac2.org/interest-groups/awareness/childhood-cancer-fact-library/

**Gold Awareness Project – The Coalition Against Childhood Cancer**

"The Gold Awareness Project offers numerous creative ways to promote powerful messages and gold icons in September to increase awareness of childhood cancer. Through this project, CAC2 hopes to inspire everyone for action and engagement locally, nationally, and globally.

The CAC2 Gold Awareness Project is determined to turn the world gold in September. The Gold Awareness Project offers CAC2 members and the wider community creative ways to promote gold and September and increase awareness of childhood cancer. The Gold Awareness Project Committee has brainstormed ideas that can be carried out by organizations and individuals to increase awareness of gold and September as the color and month representing childhood cancer. We hope these ideas inspire everyone and demonstrate that the possibilities are endless. If we each do our part in our areas of the country, an increase in national awareness will follow…”

- Included in this document are ideas about how to promote childhood cancer awareness month through: Individual Statements; School Involvement; Online Campaigns; Events; Community Recognition; Community Involvement; and Long-Term Asks, which require some preparation both before and after September to implement.
- Additionally, there are templates to help you ask your local and state officials to declare September as Childhood Cancer Month. Childhood Cancer Awareness Proclamations are available at: https://cac2.org/interest-groups/advocacy/september-proclamations/

**Advocacy**

- **Children’s Cancer Cause** is a great resource at: https://www.childrenscancercause.org/

“Children’s Cancer Cause is the leading national advocacy organization working to achieve access to less toxic and more effective pediatric cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families.
Children’s Cancer Cause leads efforts to ensure that these needs and perspectives of children with cancer are integrated into the highest deliberations on health care and cancer policy at the Federal level.”

- “Children’s Cancer Cause – The Stewart Initiative for Childhood Cancer Survivors: Policy and Advocacy” (Includes resources on advocacy and updates on policies) -
  https://www.childhoodcancersurvivorship.org/policy

- Check out https://www.congress.gov for any childhood cancer bills, and where they are at in the legislative process. For example, the Fairness to Kids with Cancer Act of 2019, “requires the share of federal funds for cancer research that is allocated to pediatric cancer research to equal the percentage of the U.S. population under the age of 18.”

- The Alliance for Childhood Cancer - https://www.allianceforchildhoodcancer.org/
  “We exist to provide a forum of national patient advocacy groups and medical and scientific organizations which meets regularly, shares ideas and concerns, and works collaboratively to advance research and policies to prevent cancer, and improve public education, and the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer.”
  - The Alliance for Childhood Cancer Action Days -

- American Cancer Society Cancer Action Network (ACS CAN) - https://www.fightcancer.org/
  “If we are to succeed in our mission to end suffering and death from cancer, it won't just happen in the doctor's office or research lab. This movement must start at the statehouse and in Congress. And, it will be led by volunteers - regular people whose lives have been impacted by cancer - rallying together to demand change from their elected officials. We are the organization empowering volunteers to do just that - influence change and impact the future of cancer. From gaining dramatic increases in funding for cancer research to ensuring all Americans have access to cancer care, our work is saving lives and leading to new innovative breakthroughs in how to fight this disease.”

- Congressional Childhood Cancer Caucus - https://childhoodcancer-mccaul.house.gov/
  Mission Statement: “The mission of the bipartisan Childhood Cancer Caucus is to serve as a clearinghouse for information on pediatric cancer and a forum to aid Members of Congress in working together to address pediatric cancer. The Caucus will strive to raise awareness about pediatric cancer, advocate in support of measures to prevent the pain, suffering and long-term effects of childhood cancers, and work toward the goal of eliminating cancer as a threat to all children.”

- National Coalition for Cancer Survivorship - https://www.canceradvocacy.org/
  - Advocacy - https://canceradvocacy.org/get-involved/


- The Childhood Cancer Fact Library from the Coalition Against Childhood Cancer -
  https://cac2.org/interest-groups/awareness/childhood-cancer-fact-library/
  This is updated on a yearly basis, and gives information, data, and statistics on childhood cancer and survivorship. Recently, international statistics and information was added.