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SIDE EFFECTS AND SUPPORTIVE CARE



Side Effects. Side effects of treatment are often a top concern. Reactions to treatment vary from patient to patient. Reactions also vary depending on:

- The treatment and/or types of drugs used
- Drug and radiation dosage
- The duration of the therapy regimen
- Whether the patient has other health conditions

Unfortunately, treatments that damage or destroy cancer cells may also affect normal cells and may cause side effects. Side effects from cancer treatment can be either short term or long term. Some side effects either improve or disappear when treatment ends, while others may show up after treatment ends, sometimes even years later. Childhood cancer survivors require close follow-up care to monitor for late effects of treatment.

It is best to address side effects right away, and there are medications and palliative (supportive) care options available to help manage some side effects. You can also help to manage side effects by making changes to your child's foods and daily activities. Talk to members of the healthcare team before making any changes.



For more information about side effects, visit www.LLS.org/booklets (filter by treatment) to view the **Side-Effect Management** series.



LLS Health Manager™ App. With *LLS Health Manager™*, you can now use your phone to manage your child's daily health by tracking side effects, medication, food and hydration, questions for the doctor, grocery lists and more. You can also set up reminders to take medications and to eat/drink throughout the day. Visit www.LLS.org/HealthManager to download.

Questions to Ask Members of the Healthcare Team

Ask your child's healthcare team the following questions about side effects:

- What side effects are common with this treatment? Can you provide a written list?
- Whom should I call if my child begins to experience a side effect?
- What side effects, signs and/or symptoms prompt a call to the healthcare team?
- What side effects, signs and/or symptoms require a trip to the emergency room?
- Is there any risk to me or others living in our household from this treatment?

Fertility Preservation. "Fertility" describes the ability to conceive a biological child. Some cancer treatments affect fertility in males and females. The risk of infertility is based on several factors including the type of treatment received, the duration or treatment dosage and the patient's age at the start of treatment. There are options to preserve fertility. Some of these options require that action be taken before treatment begins.

As much as possible, your child should be involved in the discussion about how cancer treatment may affect their ability to have children in the future. Members of the healthcare team and a child-life specialist can provide age-appropriate ways to explain and talk about these issues with your child.

Options to preserve fertility depend on whether or not your child has reached puberty and if your child needs to begin cancer treatment right away. For patients who need treatment immediately, there may not be time to complete fertility preservation.

If your child has reached puberty and time allows, sperm banking or egg freezing may be an option.

- Sperm banking (cryopreservation) for males involves the collection of semen by masturbation. If there are sperm in the semen, they can be frozen and stored at a special facility for possible future use. Sperm banking can typically be done in a short amount of time. Most male children have some sperm in their semen by age 13.
- Egg cryopreservation (freezing) for females are procedures in which mature eggs are removed from the ovary to be frozen and stored for possible use in the future. This method of freezing eggs begins with hormone fertility treatment. The patient receives daily hormone injections for about 10 days to stimulate the ovaries. The entire process generally takes 2 to 4 weeks; however, it is possible that it can be done in less time. Puberty in females usually occurs between the ages of 9 and 15 years.

For children who have not reached puberty, tissue freezing may be an option.

- Testicular tissue cryopreservation for males involves collecting and freezing a small amount of testicular tissue with the hope that the tissue will contain stem cells that would later produce mature sperm. The tissue or stem cells can be placed back into the testicle. This is considered an experimental approach. Researchers are still studying this method.
- Ovarian tissue freezing for females involves the removal of all or part of an ovary to be frozen for future use. The tissue can be transplanted to the pelvis or under the skin. This method has been considered experimental, but it is becoming a more standard option.

For some types of cancer, the doctor may advise against tissue freezing because of a concern that transplanted tissue could carry cancer cells back into the body.

In addition to sperm banking, egg freezing and tissue banking, steps may be taken during treatment to protect reproductive organs from damage or your child may have access to treatment options that are less likely to affect fertility.

Talk with your child's healthcare team about the risk of infertility based on your child's treatment plan. Many childhood cancer survivors go through puberty after cancer treatment and have children without medical intervention.



To learn more about fertility and the process of fertility preservation, visit www.LLS.org/YoungAdults or visit www.LLS.org/booklets to view **Fertility and Cancer**.

Early or Delayed Puberty. Some cancer treatments can affect the endocrine system, the glands and cells that control growth and development. Talk with your child's pediatrician if your child seems to be going through puberty early (before age 9) or has not entered puberty by age 15. The doctor will want to evaluate your child and may prescribe medicine to alleviate symptoms caused by hormone imbalance.

Premature Ovarian Failure (POF). If your child has already begun menstruating (periods) before cancer treatment, some chemotherapy drugs may either temporarily or permanently disrupt their menstrual cycle. "Premature Ovarian Failure (POF)," also called "premature menopause," is the loss of ovarian function before age 40. When POF is caused by cancer treatment, it is unlikely that a person will have subsequent menstrual periods or be able to become pregnant without medical intervention. Generally, POF is managed with hormone (estrogen and progesterone) replacement therapy.

Those who do restart menstruation after cancer treatment may still develop POF later in life. Egg freezing after cancer treatment may be an option to preserve fertility for these patients.

Palliative (Supportive) Care. Palliative care, or supportive care, is specialized medical care that focuses on providing relief from side effects and emotional stress of a serious illness, such as cancer. Palliative care provides support for both children with cancer and their families. The goal is to improve quality of life. Palliative care can be used alongside curative treatment.

Palliative care is provided by an interdisciplinary team of palliative care specialists including doctors, nurses and social workers. Other professional team members may be included and each member will be working with you, your child and the rest of your family, as well as with other members of the healthcare team, to provide an extra layer of support. No matter what type of treatment your child receives, palliative care will be available.

The type of care the palliative care team will suggest depends on the symptoms that interfere with your child's quality of life and goals for treatment. For example, if your child experiences joint pain, physical therapy may be beneficial.

Examples of palliative care include:

- Nutrition
- Physical or occupational therapy
- Pain management
- Medications to ease side effects
- Therapy or counseling
- Integrative medicine and complementary therapies
- Help with practical issues, such as managing finances or relationships
- Other medical treatments

You will work with the palliative care team to develop a plan that addresses your child's needs.

More About Palliative Care. The palliative care team communicates with every member of the healthcare team to improve overall care coordination.

- Palliative care is best delivered early in the course of the disease so that signs, symptoms and/or side effects can be controlled before they worsen or cause disruptions to the treatment plan.
- Palliative care can be provided in a hospital or at an outpatient clinic and, sometimes, at home.
- Most insurance plans cover palliative care.

You may hear people use the terms “hospice” and “palliative care” interchangeably, but they are not interchangeable. Hospice care is end-of-life care. Palliative care is appropriate for anyone who has a serious illness, regardless of age, prognosis or stage of treatment, including patients who can be cured of their disease.

As cancer treatments improve, the number of childhood cancer survivors continues to grow; however, curative treatments can still cause unpleasant side effects. Palliative care offers many ways to help your child feel better physically, emotionally and spiritually during cancer treatment and into survivorship.



To learn more about palliative care, visit <https://getpalliativecare.org/whatis/pediatric/> for resources and a provider directory.

Pain Management. A cancer diagnosis does not mean your child will have pain. However, a number of cancer patients do have pain at some point. Your child may experience pain related to the cancer or its treatment (eg, bone or nerve pain as a side effect of certain medications).

Pain may be short lived (acute) or continue longer after a disease or injury (chronic or persistent). The type and severity of pain depends on the type of cancer, treatment and the patient's overall health. Pain left untreated can suppress the immune system, delay healing and may lead to depression. The healthcare team can help determine the best plan to manage your child's pain.

Assessing Children's Pain. The healthcare team should assess your child's pain to ensure it's managed throughout treatment and recovery. Healthcare professionals often use pain scales to assess patient pain to help determine the best strategy for pain management. For children under 3 years of age or children who are nonverbal, the healthcare team may look for physical or behavioral cues to assess pain. These cues include:

- Facial expression
- Leg movement and activity such as squirming, jerking or tensing
- Crying
- Difficulty consoling or comforting the child

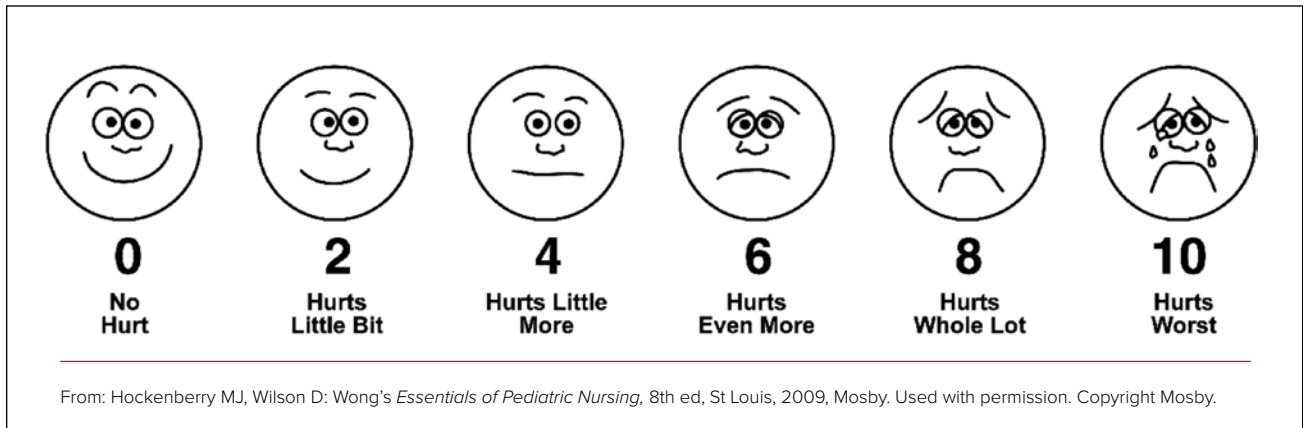
The healthcare team may ask older children and teenagers to describe or rate their pain. There are several tools the healthcare team may use that can help children to describe their pain. A tool may include a numerical scale that asks the patients to rate their pain by choosing a number from 0 to 10. A zero means no pain and a 10 means the worst pain the patient can imagine.

TIP:

You should not try to manage your child's pain with over-the-counter medications without discussing them with the healthcare team first. Some medications should not be combined with certain cancer treatments.

Another common tool is a chart with a series of faces. The child will be asked to point to the face that best describes how they feel. For example, a smiling face means no pain and a tearful face means the worst pain. See the example of the **Wong-Baker FACES® Pain Rating Scale**.

Wong-Baker FACES® Pain Rating Scale



Treatments for Pain Management. Pain management often includes a combination of medication and nondrug options to provide relief. Treatments for pain management may include:

- Medication: nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, opioid analgesics, antidepressant and anticonvulsant drugs; nerve blocks, corticosteroids, anesthetics; specialized injections, infusions; topical creams and skin patches
- Other medical interventions: medical devices, surgical procedures or treatments to address the source of the pain (eg, radiation therapy to relieve pain caused by an enlarged liver, lymph nodes or spleen)
- Psychosocial interventions: stress management, counseling, coping mechanisms
- Rehabilitation techniques: exercise therapy, application of heat or cold, myofascial therapy
- Integrative medicine and complementary therapies: acupuncture, hypnosis, yoga, aromatherapy, therapeutic massage, supplements

Consult with the healthcare team before you try complementary therapies for your child or give them new medications or supplements. Some therapies may interfere with cancer treatment.

Be persistent in working with the healthcare team to set up a pain management plan that reduces suffering and improves function. If pain is not being managed effectively, ask for a referral to a pain specialist. A child-life specialist may also be able to help address the mental and emotional side of pain management.

Supporting Your Child. Seek treatment for your child's pain early to avoid suffering and additional health problems later. Early treatment of pain is more effective than waiting until it is more severe. You or your child may be reluctant to seek pain care for the following reasons:

- Fear that seeking pain relief will distract from treating the cancer
- A false belief that relief isn't possible
- Fear that pain may be a sign of disease progression
- Worry about becoming addicted to pain medications
- Wanting to appear strong and brave
- Worrying about the side effects of pain medication

These concerns should not keep you from seeking relief for your child. Often, pain can be managed. No pain should go untreated or ignored. Unrelieved pain may cause needless suffering and suppress the immune system.

Side Effects of Pain Medications. The side effects of pain medications include:

- Constipation
- Nausea
- Drowsiness

Talk to the healthcare team about the best ways to manage these side effects.

Addiction Risk. People who have a personal or family history of substance abuse or a history of mental illness have an increased risk of developing an addiction to opioids or other medications. Tell the healthcare team about any issues in your child’s personal and family medical history that are related to mental health and substance abuse. Taking medication exactly as prescribed decreases the risk for addiction. Discuss other ways to decrease the risk of addiction with the healthcare team. Strategies may include only taking the medication for a short period of time, changing medication and using other pain management techniques. Keep all opioids and other medications in a safe and secure place in the home.

Keeping Track of Pain. Keeping a record of your child’s pain can help the healthcare team understand the nature and extent of the pain and how to manage it.



Use **Worksheet 10: Pain Log** to keep a record of your child’s pain.



For more information about pain, visit www.LLS.org/booklets to view **Pain Management Facts**.

Medical Marijuana. Marijuana has been used in herbal remedies for centuries. The biologically active components in marijuana are called “cannabinoids.” The two best studied components are the chemicals delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD). Under federal law, marijuana cannot legally be prescribed, possessed or sold. Under many state laws, the use of marijuana to treat some medical conditions is legal. Under some states laws, the use of recreational marijuana by adults is legal. (Even in these states, its use is still illegal for minors.)

In cancer care, medical marijuana is sometimes used to manage side effects such as nausea, appetite loss, pain or anxiety if other medications or treatments are unsuccessful. More research is needed to better understand the benefits and risks of marijuana and its cannabinoids.

Do not give your child marijuana or products made with cannabinoids without first talking to the healthcare team.

Marijuana or related products (for example, CBD oils) could interfere with other medications. If your child is a teenager, talk to them about marijuana use, even if you do not believe they use marijuana or related products. Marijuana products that are not obtained from licensed dispensaries carry additional risks as they may contain unknown ingredients, including infectious agents. Encourage your child to talk honestly with members of the healthcare team. Your teenager may wish to speak to members of the healthcare team privately.

Blood Transfusions. Blood cells donated by healthy volunteers are given to patients to improve their blood cell counts. Patients receiving chemotherapy may require blood transfusions as part of supportive care during intense phases of treatment. Blood products are specifically matched to the individual patient, and the patient is very carefully monitored during the transfusion for potential reactions. Transfusions can last several hours.

Blood Components. When a patient receives a transfusion, they won't be getting whole blood. Instead, the patient will receive components of blood that has been filtered. Components that the patient can receive separately by transfusion are:

- Red blood cells
- Platelets
- Granulocytes (white blood cells)
- Plasma and cryoprecipitate
- Gamma globulin
- Albumin

White blood cell transfusions are uncommon.

Blood Transfusion Safety. Many patients and caregivers are concerned about blood supply safety. The good news is that the risk of transmitting viral diseases, such as human immunodeficiency virus (HIV) and hepatitis, by blood transfusion has dropped dramatically because of a multilayered approach to safety. Today, 12 different tests are performed on each unit of donated blood to check for infectious diseases.

Complications of Blood Transfusions. Most patients who receive a transfusion don't suffer any adverse reactions. However, it's still possible for reactions to occur with any blood component. A reaction can occur both at the time of the transfusion or weeks or months later. The doctor may prescribe medication before the transfusion to reduce the risk of side effects.

During the infusion if you or your child notice any of the following signs and/or symptoms, however slight, alert the nursing staff immediately to prevent avoidable complications:

- Fever
- Rash or hives
- Chills
- Nausea
- Pain at the transfusion site
- Back pain
- Shortness of breath
- A drop in blood pressure
- Dark or red urine

Reactions that aren't immediate include:

- Alloimmunization. This occurs if the body produces antibodies against certain antigens in transfused blood. Alloimmunization may not cause immediate signs and/or symptoms, but the healthcare team will need to take special precautions if the patient receives more transfusions.
- Iron overload. If the patient receives ongoing red blood cell transfusions, they are at risk for developing iron overload. If it is not treated, iron overload can damage the heart and liver. The patient may need medication to remove excess iron from the body.
- Cytomegalovirus (CMV) transmission. Cytomegalovirus is a virus that can cause serious problems (eg, pneumonia) for immunosuppressed patients.

- Viral infection transmission
- Bacterial infection transmission
- Graft-versus-host disease (GVHD)

Most of these reactions are either rare or manageable, thanks to new procedures and precautions for blood transfusions. If you have concerns about blood transfusions, talk to members of your child's healthcare team.



For more information about blood transfusions, visit www.LLS.org/booklets to view ***Blood Transfusion.***
