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SIDE EFFECTS AND SUPPORTIVE CARE

Visit www.LLS.org/CaregiverWorkbook to access all chapters and worksheets.

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

- The treatment and/or types of drugs used
- Drug or radiation dose amounts
- The duration of the therapy
- Whether the patient has some other health condition, such as diabetes or kidney disease

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 other may show up after treatment ends, sometimes even years later.



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



LLS Health Manger™ App. With LLS Health Manger™, you can now use your phone to manage your loved one'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 for your loved one's medications and for them to eat/drink throughout the day. Visit www.LLS.org/HealthManager to download.

Palliative (Supportive) Care. Palliative care, or supportive care, is specialized medical care that focuses on providing relief from the side effects and emotional stress of a serious illness, such as cancer. The goal is to improve quality of life for both the patient and the family. 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, family members and your loved one, as well as with the other members of the healthcare team, to provide an extra layer of support.

The type of care the team will suggest depends on the signs and/or symptoms that interfere with the patient's quality of life and goals for treatment. For example, if joint pain causes mobility issues, the patient may benefit from physical therapy.

Examples of palliative care include:

- Nutrition
- Physical or occupational therapy
- Pain management
- Medications to ease side effects

TIP:

Palliative (supportive) care is appropriate for anyone who has a serious illness, regardless of age, stage of the disease or prognosis.

- Therapy or counseling
- Help with practical issues, such as managing finances or relationships
- Other medical treatments

Your loved one will work with the palliative care team to develop a plan that addresses their 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 the patient can gain control of symptoms before they either 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, including Medicare and Medicaid, 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 can be used by any person who has a serious illness, regardless of age, prognosis or stage of treatment. Palliative care may also be useful for patients who are newly diagnosed.

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

Caregiver Responsibilities. If your loved one is suffering from pain or other signs and/or symptoms caused by cancer or the side effects of treatment, ask the healthcare team for a referral to a palliative care specialist. To help your loved one manage gastrointestinal side effects (such as nausea, diarrhea, or constipation) or weight loss or weight gain, you can ask for a referral to a registered dietitian.

Pain Management. A cancer diagnosis does not mean that your loved one will have pain. However, a number of cancer patients do have pain at some point. Your loved one may experience pain related to the cancer, its treatment or other coexisting diseases (for example, arthritis). 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. Your loved one should not try to manage pain with over-the-counter medications without discussing them with the healthcare team first. Some medications should not be combined with certain cancer treatments. The healthcare team can help determine the best plan to manage your loved one’s pain.

Treatments for Pain Management. The healthcare team should assess your loved ones’ pain and ensure it’s managed throughout treatment and recovery. Pain management often includes a combination of medications 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 (for example, radiation therapy to relieve pain caused by 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 your loved one tries any complementary therapies or takes 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 the pain is not being managed effectively, ask for a referral to a pain specialist.

Supporting Your Loved One. As a caregiver, encourage your loved one to seek treatment for pain early to avoid suffering and additional health problems later. Early treatment of pain is more effective than waiting until it is more severe. Your loved one 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 meds
- Wanting to appear strong and brave
- Worrying about the side effects of pain medication

These concerns should not keep your loved one from seeking relief. Pain can be managed. No pain should go untreated or ignored. Unrelieved pain may cause needless suffering and suppress the immune system.

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 opioid medications. If this applies to your loved one, encourage them to discuss concerns and options with the healthcare team. Taking medications as prescribed by the doctor greatly reduces the risk of addiction. Discuss other ways to decrease the risk of addiction with the healthcare team. Strategies may include only taking medication for a short period of time, changing medication and using other pain management techniques.

Keeping Track of Pain. Keeping a record of your loved one's pain on a daily or weekly basis can help the healthcare team understand the nature and extent of the pain and how to manage it. You can help your loved one track and record their pain.



Use **Worksheet 10: Pain Log** to keep a record of your loved one's pain.



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

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 state 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.

Encourage your loved one to talk honestly with their healthcare team before they use marijuana or products made with cannabinoids and/or about any current use of marijuana. Marijuana or related products (for example, CBD oils) could interfere with other medications. Marijuana products that are not obtained from licensed dispensaries carry additional risks as they may contain unknown ingredients, including infectious agents.

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 dosage of treatment 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.

Options to preserve fertility depend on several factors. If a patient needs treatment immediately, there may not be time to complete the fertility preservation process. Options can include:

- Sperm banking
- Egg or embryo (egg fertilized with sperm) freezing

Other more experimental options may also be available. Your loved one may also be able to take steps during treatment that will reduce the chance of infertility, such as using shields during radiation therapy or choosing different treatment options, if available.

Remember, there are many ways to build a family, whether through natural conception, using assisted reproductive technology, or adoption. When your loved one is ready to start a family, they can consider and discuss all options with their healthcare team.



For more information about fertility, visit www.LLS.org/booklets to view *Fertility and Cancer*.

Blood Transfusions. Blood cells donated by healthy volunteers are transplanted into patients to help replace red blood cells, platelets and other blood components. Some blood cancer patients need periodic blood transfusions to improve blood counts.

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

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, multiple 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 the patient experiences any of the following signs and/or symptoms, however slight, alert the nursing staff promptly to prevent avoidable serious complications. Look for:

- 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 (for example, 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.



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

Caregiver Responsibilities During Blood Transfusions. As a caregiver, you can accompany your loved one to the blood transfusion appointments. Transfusions can last for several hours. Keep an eye on your loved one and report any side effects that occur, either during or after the transfusion, to the healthcare team immediately.

Questions to Ask Members of the Healthcare Team

- What side effects are common with the patient's treatment? Can you provide a written list?
- What side effects, signs and/or symptoms prompt a call to the healthcare team? What is the best way to reach the healthcare team?
- What side effects, signs and/or symptoms require a trip to the emergency room?
- Can the patient be referred to palliative (supportive) care to help manage side effects?

