8 END OF THE CAREGIVER ROLE

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

If your loved one successfully completed treatment, you may find it difficult to stop being the caregiver for your loved one. You will both be transitioning out of your roles as caregiver and patient. If your loved one has advanced cancer and chooses not to continue treatment, you will need to consider hospice or end-of-life care. If your loved one dies, you will need time to mourn. In the following sections, learn more about what happens once treatment ends.

Transitioning Out of the Caregiver Role and Into Survivorship. During cancer treatment, you played an important role in supporting your loved one. You may have provided physical, emotional, and practical care on a daily basis for months. At some point, the need for the type of care you gave will come to an end.

Discussing Continued Needs. Once treatment is completed, your loved one may still need your help for some time while he or she is recovering from treatment. Transitioning out of the caregiver role can be a gradual process. Talk to your loved one about what he or she needs and how you can help. If your loved one is able to take on a more independent role, be supportive and allow him or her to do so. Keep the lines of communication open. The end of treatment is a good time to revisit the boundaries and parameters you may have set when your loved one started treatment.

To update parameters, use **Worksheet 4: Questions for Caregivers to Ask Their Loved Ones.**

Finding Your New Normal. Many people refer to the time after cancer treatment as the "new normal." For patients and caregivers, it may not be possible for life to return to exactly the way it was before cancer. Be careful to manage your expectations. It may not be possible, for practical reasons, to resume the schedule or lifestyle you lived before your loved one was diagnosed with cancer. For example, you may have had to quit your job to care for your loved one. Or, perhaps you have gained a new perspective from your time as a caregiver and maybe you don't want to go back to the way things were.

The following tips may help you find your "new normal" after caregiving:

- Go back to work. If you had to take a leave or if you left your job entirely, try going back to work. Reach out to your past employer or seek a new job. Working and having a regular schedule will help you adjust.
- Reach out to friends and family members. Your social life may have been put on hold while caring for your loved one. Rekindle these relationships.
- Try volunteering. If you are retired or if you find yourself with free time on your hands, volunteer with a local organization. It doesn't have to be a cancer organization. (In fact, it may be easier for you emotionally if it isn't.) What cause do you care about—animals, education, hunger, the environment?
- Take care of yourself. Now, you can focus much more on yourself. Improve the food choices you make. Stop smoking. Be more active. Do something you love—travel, write, or pursue any other hobby you enjoy.

Caregiving After Cancer Treatment. After cancer treatment ends, you most likely will not be providing the same level of care, but there are still things you can do to support your loved one during survivorship. For example, you can

- Learn about the possible late side effects that may follow the patient's treatment. Keep an eye out for them.
- Go with your loved one to follow-up appointments and scans.
- Help your loved one to collect medical records as he or she transitions back to a primary care provider instead of receiving care from an oncology healthcare team.
- Be there for your loved one to offer emotional support.
- Work with members of the healthcare team and your loved one to create a survivorship care plan. The plan includes
  - A summary of diagnosis and treatment
  - A plan for follow-up care, a screening/testing schedule, and side-effect management, including which members of the healthcare team will be responsible for each aspect of the plan.

The ASCO Survivorship Care Plan: American Society of Clinical Oncology (ASCO) provides downloadable templates for patients to fill out with their healthcare team. Visit **www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans** to download a template. .

> **"I would suggest [taking] a few minutes to remember the things that you love. Remember the things that make you happy, whether it be gardening or whatever you would do if you had a whole lot of down time, because, as a caregiver, you don't have a lot of down time. Do some research and look for whatever it is that you love and pursue that. Life is too short."**
>
> *—Kimberly, caregiver and wife of Elijah, who passed from myeloma*
>
> Excerpt from July 2018 "No Playbook for Caregiving: Kimberly's Story" podcast episode on *The Bloodline with LLS (www.LLS.org/TheBloodline)*

Managing Fear of Recurrence. Fears of recurrence, even years into remission, are normal. As a caregiver, you are likely to be concerned about this too.

Educate yourself. Know the risk of recurrence and what can be done to lower the chances. Talk to members of the healthcare team.

Survivorship can be a difficult time, too. Treatment offers a clear goal and an end date. Without some sort of structure like this, you and your loved one may feel lost. As you transition out of the caregiver role and your loved one transitions to survivorship, take things one day at a time.

End-of-Life Care and Hospice Care. If your loved one chooses to stop treatment, you will need to consider hospice care.

Choosing to Stop Treatment. At some point during the cancer journey, your loved one may need to think about stopping treatment. This can be a difficult choice to make. Further, a decision to stop treatment is likely to bring up strong feelings for everyone involved.

It may be time to consider stopping treatment when

- Your loved one has exhausted multiple lines of treatment options without improvement or with continued disease progression.
- Your loved one's quality of life has declined drastically without hope for improvement.
- Your loved one is too sick to continue treatment safely.
- Your loved one explicitly says that he or she no longer wants to seek treatment.

Discuss Options With the Healthcare Team. If additional treatment will not increase life expectancy, do so minimally, or perhaps even decrease quality of life for your loved one, it may be time to consider how to approach end-of-life care. Your loved one may or may not be ready for this discussion or may not want to have any part of it. The timing and presentation of these concerns must be carefully considered.

Ultimately, your loved one's decision is a personal one. Deciding to stop treatment is not "giving up." Whether or not you wish that your loved one would carry on with treatment, support his or her wishes. You are the caregiver, so, at a time like this, you may need to remind other family members and friends who may disagree with the decision that their loved one's wishes must be respected.

The end of life is a challenging and emotional time for the caregiver and the patient (as well as for family members and friends). Providing care that makes your loved one as comfortable as possible and improves quality of life in any way is essential. "Comfort care" of this kind will likely free up emotional and mental space so that your loved one can live out his or her days in ways meaningful to him or her. For example, for some people this may be a time of introspection and reflection, for others it may mean spending more time with family members or friends.

Financial Matters. The costs of end-of-life care can be considerable. Financial stress at this time is common, and financial issues are important. Families deal with terminal illness and financial concerns in different ways. It's important to not feel guilty if you and your loved one have concerns about financial matters.

Questions to Ask Members of the Healthcare Team

- What are the chances of recurrence?
- What can your loved one do to lower the risk of recurrence?
- What signs and/or symptoms should my loved one look for to know if the cancer has returned?
- Will additional treatment increase life expectancy and for how long?
- How will additional treatment affect my loved one's quality of life?

Although no single resource exists that fully address a family's financial concerns, an Information Specialist at **(800) 955-4572** from The Leukemia & Lymphoma Society (LLS) can provide information and referrals to help you.

Hospice. Hospice embodies a philosophy that delivers compassionate care to people who are approaching the end of their lives and provides emotional and physical support to them and their loved ones. Hospice offers medical care that focuses on maintaining or improving the quality of life for someone whose illness, disease or condition is unlikely to be cured. An interdisciplinary hospice team provides medical care, pain control and emotional and spiritual support that is tailored to the individual needs of each patient and his or her family. The hospice philosophy also encompasses the belief that each and every person has the right to die with dignity and without pain, and that families should receive the help and support needed to participate in this process.

Most hospice programs enable the patient to stay at home. However, some are freestanding centers that are affiliated with hospitals or nursing homes. The hospice team is usually comprised of hospice doctors, nurses, social workers, home health aides, volunteers, and chaplains and other pastoral counselors.

Some of the services provided include

- Pain management
- Emotional and spiritual support
- Family coaching
- Provision of drugs and medical supplies
- Home health aide placement and supervision.

Your loved one may be eligible for hospice

- If he or she has a life expectancy of 6 months or less
- If he or she decides to stop receiving treatment
- If he or she can no longer safely receive treatment.

Talk to the healthcare team if your loved one is making many trips to the emergency room but would rather just stay at home, or if you, as the caregiver, can no longer meet the demands of your loved one's daily, ongoing medical or care needs. Ask if hospice care is an option your loved one might consider now.

You can either ask a member of the healthcare team for referral to hospice or contact the following organizations for more information about hospice:

- National Hospice and Palliative Care Organization at **www.nhpco.org**
- Hospice Foundation of America at **www.hospicefoundation.org**

Physician Order(s) for Life-Sustaining Treatment (POLST) Paradigm. "Physician Orders for Life-Sustaining Treatment (POLST)" are medical orders for a person who has a progressive serious illness or who is nearing the end of life. These orders are sometimes referred to as "medical order(s) for life-sustaining treatment (MOLST)" or by other names, depending on the state you live in. A POLST form is completed by the doctor with input from the patient or the patient's healthcare agent. It specifies the treatment(s)/intervention(s) the patient wants to receive during a medical emergency. Pain management and comfort care will always be a priority. Based on your loved one's preferences and priorities for end-of-life care, he or she may choose to decline other medical interventions. POLST forms differ by state and not all states have a standardized form yet. Visit **https://polst.org/programs-in-your-state** for more information.

A POLST form may address decisions about

- Attempting cardiopulmonary resuscitation (CPR)
- Implementing intubation and mechanical ventilation
- Providing artificial nutrition and hydration (tube/intravenous feeding)
- Use of antibiotics
- Pain management
- Transfer to an emergency room or the hospital.

FACT

A POLST form differs from an advance directive. Ideally, everyone will have an advance directive in place; a POLST form, however, is only created for people who have a progressive serious illness (for example, Alzheimer's disease) or those who are nearing the end of life. It is completed and signed by the patient (or the patient's healthcare agent) and the doctor.

Orders on a POLST form can always be cancelled or updated.

Other orders used in end-of-life care include "do not resuscitate (DNR)" and "allow natural death (AND)" orders which instruct healthcare professionals that CPR is not to be attempted. These may be separate orders or included on a POLST form.

Visit the National POLST Paradigm at **https://polst.org/programs-in-your-state** to find out more.

For more information on advance care planning, visit **www.LLS.org/booklets** to view, print or order the free LLS booklet ***Advance Care Planning.***

In-Home Hospice Care and Caregiver Responsibilities. If your loved one receives in-home hospice care, as the caregiver, you will still be providing care for your loved one, but alongside and with the members of the hospice team. With in-home care, a healthcare professional will not be present at all times, but a nurse will visit your loved one on a regular schedule. The hospice team will teach you how to

- Administer medications
- Care for an intravenous (IV) line, central line, percutaneously inserted central venous catheter (PICC) or port
- Use any necessary medical devices or equipment
- Provide nutrition
- Make your loved one comfortable
- Assist with bathing, and skin and mouth care.

Your loved one should not be left alone as his or her life draws to its close. Work with family members, friends and the hospice team to coordinate round-the-clock care.

TIP:

Even during the time that you are taking care of your loved one at the end of his or her life, you must remember to take care of your own health and well-being, too. Lean on family and friends during this difficult time. Try to take time for yourself to rest and recuperate so you can provide the best care for your loved one.

Pain Management Near the End of Life. As the end of life approaches, your loved one may be in pain. Seeing your loved one suffer, especially for a long time, can be upsetting and frustrating. The hospice team will help with pain management and make your loved one more comfortable. In a hospice setting, pain management often involves strong medications. These medications may be given orally or intravenously. A member of the hospice team will teach you how to administer them. If your loved one's pain is not controlled by the prescribed medication or dosage, let the hospice team know as soon as possible so that the doctor can make the necessary adjustments. Pain is more difficult to control if it is allowed to build up. Other pain management methods, such as massage, may also be used.

Making the Most of Time Left With Your Loved One. Hospice care is provided in a comfortable, private space (at home, for example) instead of in a hospital or treatment center. This means that you and your loved one and his or her family and friends will have the opportunity to spend more quality time together. Let your loved one take the lead and indicate how he or she would like to spend this time. You might want to

- Reminisce and share fond memories, photographs, and home videos
- Watch favorite films or listen to favorite movies
- Arrange visits or phone calls from family members or friends if your loved one would like to see or talk to people
- Write down any memories or messages that your loved one would like to share
- Tell your loved one that you love him or her and acknowledge any support or kindness your loved one has given you and thank him or her for caring.

TIP:

Caring for a loved one at the end of his or her life is a tremendous responsibility. As a caregiver, you provide invaluable support, care and comfort to your loved one during a difficult time. Be gentle with yourself and take care of yourself, too. When your caregiving role comes to an end, you will also need healing time.

The Dying Process. Dying can be a slow process. The hospice team will help you prepare and know what to expect. For in-home hospice care, you will also need to know what to do and whom to contact when your loved one dies. The hospice team will provide you with instructions.

If your loved one dies while not under hospice care, call 911. Let the 911 operator know that the death was expected and that no emergency exists. If your loved one has a DNR or POLST form, give the form to the paramedics when they arrive. If your loved one does not have a DNR or POLST form, the paramedics may begin CPR and/or bring the patient to the emergency room. Law enforcement may ask you or other people in the home about your loved one's condition. Ask members of the healthcare team the procedure you should follow if your loved one dies.

As your loved one's life draws to its close, there are things you can do to make him or her more comfortable. For example, you can

- Talk to your loved one even if it seems as though he or she can't hear you.
- Try to fulfill any requests such as favorite foods, music or pictures.
- Use pillows or adjust the bed to keep your loved one's head elevated so it is easier for him or her to breathe and swallow.
- Wash your loved one's face and hands gently with a warm washcloth.
- Put a disposable pad on the bed to help with cleaning up waste.
- Keep your loved one's mouth, lips, and nostrils moisturized and lubricated to prevent cracking and dryness.
- Clear debris around oxygen tubes.
- Care for your loved one's skin by keeping it clean, dry and moisturized.
- Help your loved one turn or change positions on the bed to prevent bed sores and cramps.

In the days or weeks leading up to death you may notice the following changes in your loved one's conditions:

- Changes in his or her sleeping patterns
- Pain that is more difficult to control
- Weakness increases
- Decreased appetite
- Changes in cognitive function (eg, confusion, hallucinations, or vivid dreams).

Questions to Ask Members of the Hospice Team

- **What should my loved one and I expect during this time?**
- **Can I receive all care instructions in writing?**
- **Whom can I call with general questions?**
- **Whom can I call after hours in an emergency situation?**
- **What signs and/or symptoms require a call to the hospice team?**
- **What medical equipment or supplies will be provided?**
- **What is the schedule for visits from members of the hospice team?**
- **What are the signs and/or symptoms that mean death is near?**
- **What do I need to do when my loved one dies?**

In his or her last weeks or days, your loved one will likely experience a wide range of feelings and, sometimes, conflicting emotions. He or she may wish to see and speak with family members or friends. Or, he or she may become withdrawn. Your loved one may worry or seem agitated.

Death can bring with it fear and suffering but, remember, it can be gentle too. As life draws to a close, your loved one may even welcome death and the peace it can bring with it. When you sense the time is right, you may be able to help your loved one. Perhaps that means finding a way to let your loved one know that the struggle is almost over, that he or she can rest now and just "let go." To you, this may feel almost like giving him or her "permission" to die.

As death draws closer, there may be

- Loss of bladder or bowel control
- Drifting in and out of different levels of awareness or consciousness
- Changes in breathing, faster or slower, a different rhythm
- Bluish tint to the skin, starting with the hands and feet.

Bereavement. Despite the intense emotions experienced by many bereaved persons, most grief is a normal, albeit painful reaction, to the loss of a loved one. Everyone expresses grief in his or her own way. Although grief is not bound by time, the intensity of normal grief does heal over time as the bereaved person adjusts to the loss of his or her loved one.

Grief can affect each person emotionally, physically, cognitively and behaviorally. These aspects of grief manifest themselves in many ways. For instance

- Emotional effects include feelings of sadness, anger, guilt, self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief, numbness.
- Physical effects include the sensations of hollowness of the stomach, tightness of the chest, tightness of the throat, oversensitivity to noise, sense of depersonalization, breathlessness and shortness of breath, weakness of the muscles, lack of energy, dry mouth.
- Cognitive effects encompass disbelief, confusion, preoccupation, a sense of presence, hallucinations, lack of focus.
- Behavioral effects manifest as sleep disturbances, appetite disturbances, absent-mindedness, social withdrawal, dreams about deceased loved ones, searching and calling out, sighing, restlessness, crying, visiting places or carrying objects, treasuring objects.

Different Ways of Expressing Grief. Many people express grief in an outward way; for example, crying, a lack of energy or trouble sleeping. Others, on the surface, may not seem to be grieving. Instead, these people process grief internally. Their grief may go unrecognized and unacknowledged. Be aware that grief is personal and specific to the person. Try not to make judgments about how you (or others) process the loss of your loved one. The manner and timing of your approach to your loss and how you work through your grief depends on you as an individual.

TIP:

Be kind and patient with yourself. Everyone experiences and processes loss differently. Do not feel pressured to grieve in a specific way. Allow yourself the time you need to feel your emotions and to heal.

Children and Grief. Children may not be able to fully comprehend the nature of death until they're about 10 years old. However, children are capable of sensing separation and experiencing grief at a very young age. Children's grief is different than that of adults. The ways in which children experience and express grief depends on their development level. Their grief may also be cyclical. Children will grieve within the confines of their developmental stage and then when they are more developmentally advanced, they may revisit their loss and grieve for their loved one all over again.

Ways to Remember Your Loved One. As time passes and your grief becomes more manageable, you may search for ways to remember the person you lost. There are many ways to do so. Some of the following ideas may help you to honor your loved one's memory:

- Visit your loved one's resting place if he or she chose to be buried, or visit a favorite place where you spent time with your loved one, such as a park.
- Frame an item of clothing, an accessory, or some other token that reminds you of your loved one.
- Create a scrapbook with some of your favorite photos, cards or letters.
- Plant a flower or tree in your loved one's memory.
- Invite friends and family over on a special date to share fond memories of your loved one.
- Volunteer for an organization in your loved one's memory.

Honor your loved one in a way that is meaningful to you and in a way that brings you comfort. You can do so alone or you can ask friends and family to join you.

Seeking Support. Sometimes, a person may become stuck at some point in the grief journey or express grief in an unhealthy way. If you find yourself unable to return to daily life or find enjoyment, even if it's some time after your loved one has passed, seek the services of a grief counselor or professional therapist.

For counseling and bereavement support group referrals, speak with an LLS Information Specialist at **(800) 955-4572**.

You may also want to join the bereavement group on LLS Community to connect with other caregivers who have lost a loved one. Visit **www.LLS.org/community** to sign up.

End of the Caregiver Role Notes

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