



## Caregiving and Making Treatment Decisions for Adults with Advanced Cancer

Caregiving for your loved one with advanced cancer is full of transitions. You may feel like your role as a caregiver has changed over time. This is a hard period for both you and your loved one. You may find you are having conversations that are uncomfortable or sad. Understand that these are important conversations to have, even if at times, they are hard to hear. This booklet has information to help you and your loved one have these conversations and make treatment decisions. This resource also has important tips to help you advocate for your loved one's treatment wishes and needs.

Family members, spouses, partners, and other loved ones may help patients make treatment decisions. Caregivers may become the primary decision-maker in a loved one's cancer care for different reasons. A loved one may have cognitive or mental health disabilities. A brain metastasis or stroke may impact a loved one's ability to make decisions. Or a loved one's cancer may progress far enough that they feel too sick to make decisions themselves.

Speaking to your loved one about their goals while they are well may make it easier to focus on more difficult issues later.

### **TREATMENT OPTIONS AND DECISION MAKING**

When your loved one has advanced cancer, it is important to ask about all treatment options available.

Treatments that were not an option at time of diagnosis could be treatment options now. New treatments may have become available, or treatments ruled out earlier may now be a better fit. One such option may be precision medicine. If you and your loved one have never talked about precision medicine and biomarkers with their care team, now may be a good time to ask about it.

**Precision medicine** is a newer way to find the right treatment for patients. Before, cancers were treated based on the type of cancer (such as lung or breast cancer). Precision medicine allows doctors to use biomarker testing to find your loved one's subtype of cancer.

Biomarker testing helps the doctor match the right drugs to the specific subtype of your loved one's cancer. In biomarker testing, a sample of their cancer is collected from their blood, bodily fluids, or tissue taken during surgery or biopsy. The sample is sent to a lab. The test looks for biomarkers in the cancer sample. The test results can be used to help guide their treatment options.

Biomarkers are often referred to by a 3 or 4 letter abbreviation. Examples of biomarkers are HER2 in breast cancer or EGFR in lung cancer. A positive test (HER2+ or EGFR+) means the cancer's genes have that mutation.

Ask your care team if biomarker testing is appropriate for your loved one's stage and type of cancer. Biomarkers may help the care team find new or different treatments for your loved one's cancer.

Biomarker testing is different from genetic testing. Genetic testing is used to detect DNA changes that suggest a mutation. Some inherited genetic mutations can increase cancer risk. If you want to learn more about genetic testing ask your care team about meeting with a genetic counselor. To learn more about precision medicine and biomarker testing visit [www.CancerSupportCommunity.org/precision-medicine](http://www.CancerSupportCommunity.org/precision-medicine).

## DECISIONS IN ADVANCED CANCER

If the cancer is advanced or cannot be cured, the decisions you and your loved one will be making may be about quality of life or length of life. You may be focusing on finding treatments that cause the fewest number of side effects or limit the time spent in the hospital. These decisions can be difficult to make. It is important for you and your loved one to think about what is important to them and how they want their life to be, so they can make the best decisions. Having open and honest conversations with the care team may be beneficial.

If you are having trouble getting started with these conversations, ask to connect with a social worker or counselor familiar with cancer. They can help you talk through feelings and fears so that you can get the conversation started.

### CANCER SUPPORT HELPLINE®

If you need help finding resources or want help getting information about cancer, call the **Cancer Support Helpline®** at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday-Friday 9:00 a.m.-8:00 p.m. ET and Saturday 9:00 a.m.-5:00 p.m. ET.



## QUESTIONS TO ASK THE CARE TEAM

When the care team presents options, it is important to ask questions. Think about what information you need to feel ready to make a decision. Here are some questions to guide the conversation.

What is the goal of the treatment?

What are the potential benefits of the treatment?

What are the potential side effects of the treatment?

How will their quality of life and daily activities be impacted?

What support is available to help us? (examples: patient or financial navigation, support groups or counseling, etc.)

### CLINICAL TRIALS

Consider talking to the care team about clinical trials. Clinical trials are research studies that compare known treatments with a new approach. Clinical trials help patients access the newest developments in cancer research.

Not all clinical trials test cancer treatments. Some clinical trials test new ways to improve the quality of life for people with cancer.

For more information about clinical trials, visit [www.CancerSupportCommunity.org/clinical-trials](http://www.CancerSupportCommunity.org/clinical-trials)





## ADVANCE CARE PLANNING

Advance care planning is the ongoing process of making decisions about what a person wants. It is important to think about what decisions may need to be made. When talking with your loved one about advance care planning, consider their goals and their values. One of the most important parts of advance care planning is making sure the plan is updated and shared with relevant people. Your loved one's wishes and goals for treatment may change over time. Check in with them often to make sure that you and the care team are aware of what they want.

Some medical decisions can be organized in an advance directive. An **advance directive** is a legal document that is used to make medical decisions if your loved one is unable to make those decisions themselves. In order to decide what information to include in the advance directive, you and your loved one can talk with the primary care team.

There are two types or parts of an advance directive: a living will and durable power of attorney for health care.

- The **living will** typically includes decisions about end-of-life care. Often, it will include specific instructions about what medical measures can be taken.
- The **durable power of attorney for health care** states the person your loved one would like to make their medical decisions for them if they are unable. This can also be called medical power of attorney or healthcare proxy. Examples of proxies include a spouse, adult child, parent, or another person they trust.

In some states, an advance directive may need to be signed by a witness. A social worker may be able to help you understand the process where you live. Once the advance directive is completed, give a copy to your loved one's care team and make sure that the health proxy is aware of their role.

If your loved one is approaching end of life, talk about and complete other advance care documents about their wishes. A **do not resuscitate** (DNR), do not intubate (DNI), or allow natural death (AND) order tells the health care team if your loved one wants certain measures to be taken. An example is deciding that they do not want a machine (a ventilator) to breathe for them or to have their heart shocked if their lungs or heart stop working.





## PALLIATIVE CARE

When living with advanced cancer, feeling good day to day is an important part of making treatment decisions. Palliative care is a type of care that focuses on providing relief from the stresses and symptoms of serious illness. It does not treat the cancer itself. Its goal is to improve how your loved one feels. Palliative care specialists are highly skilled in treating the symptoms of cancer and the side effects of treatment. Ask if palliative care can be a part of your loved one's health care team. A palliative care team offers an extra layer of support and can be available throughout treatment. The team may include doctors, nurses, social workers, and other specialists. Palliative care is not the same as hospice or end-of-life treatment.

## HOSPICE CARE

Hospice care is physical, social, spiritual, and psychological care given to people who have stopped treatment of their cancer. Its focus is on maximizing end-of-life comfort and quality. Depending on what is available where you live, hospice care can be given at home, in a nursing facility, or in some cases, a special facility. In many cases, hospice is the best way to remain at home instead of spending time in the hospital. It can be helpful to talk about hospice early to make a plan with the care team. If your loved one chooses to have hospice care, their doctor will refer them to a hospice provider. And if your loved one already works with a palliative care team, they can continue to during hospice care. If you want to learn more about what hospice providers are available in your area, call your loved one's insurance provider or ask to speak to a social worker.



Like the cancer care team, hospice care teams include multiple professionals. The hospice team may include doctors, nurses, social workers, nursing aides, and spiritual supports. Though the patient is the focus of the hospice care team, they will also support caregivers and loved ones.

Ask your health care team about hospice early in your loved one's treatment. Many people are referred to hospice later than they could be. That means that they and their families miss the opportunity to benefit from everything hospice care can offer.

## CARE TEAM CHANGES

Throughout your loved one's cancer care, they may have multiple care teams. Some specialists work with your loved ones at the same time, others may "take over" at different times. You can help during these transitions by making sure to have all necessary records, scans, and treatment summaries. If you are moving within a hospital system, the new care team may have access to these records.

In some cases, you may be able to share records through the electronic medical record system. Or you may need to request records to be printed, sent, or put on a disc for new providers. Talk to both care teams to learn what types of information should be shared and the preferred format. Ask if there is a patient navigator or care coordinator who can help you during these changes.

## COST OF CARE

While making treatment decisions, you and your loved one may be thinking about the cost of care. Managing cancer related costs can be a stressful aspect of care. If the cancer advances, review your loved one's health care coverage to see if they are eligible for any financial assistance like prescription copay assistance, disability, or different health care plans.

It can be helpful to keep bills and documents organized. Talk with your loved one's doctor about what costs to expect and how they may change. Ask to speak with a social worker or financial navigator to learn more and see what options are best for you.

### MYLIFELINE®

MyLifeLine® exists to easily connect cancer patient and caregiver with friends and family in order to reduce stress, anxiety, and isolation. By creating your own private website, you can document your journey and ask for support from friends and family. They want to help. Use the Helping Calendar to organize things you need help with, such as meals, rides to appointments, childcare, and other events. Visit [MyLifeLine.org](https://www.mylifeline.org) to make your own website today.



## ADDITIONAL SUPPORT

There may come a time when you and your loved one decide that you both need additional support at home. Daily activities may have become more difficult or tiring to complete. It may be time to see what additional support is available. Consider other people who may be able to help with caregiving. Ask if there are tasks family and friends can help with from a distance. If you need more structured or technical supports, talk to the care team about help finding skilled nursing support. Depending on coverage and your loved one's condition, some skilled nursing may be covered by insurance.

Respite care is short-term, temporary relief to primary caregivers who support an ill loved one. Respite care offers a way for caregivers to take a break. You may use respite care for a few hours, a full day, several days, or weeks. It may be provided in your home, in a nursing home, or in an adult day care center. It is often a positive experience for everyone involved. You can contact a respite care organization when you need time away. To find such a program or learn more, visit [www.archrespite.org](http://www.archrespite.org).

## TAKING CARE OF YOU

Being the primary decision maker for your loved one can feel like a lot of pressure. As you are advocating for your loved one, also consider your needs. Make sure you are eating, getting enough sleep, and exercising. Think about who is your support network. You will be a better caregiver when you are taking care of yourself.

If you are feeling distressed, sad, or overwhelmed, ask if you can speak with a social worker. They may be able to refer you to support groups and other resources specifically for caregivers in your position.



## APPLY FOR FMLA

You might have found your caregiving responsibilities are taking more of your time. It may be a challenge to balance work, caregiving, and daily tasks. If available to you, consider applying for FMLA benefits. In the U.S., FMLA or the Family Medical Leave Act protects employees' jobs when they need to take time away from work to care for their own or a family member's serious medical condition. Under FMLA you can take up to 12 weeks of unpaid job protected leave. Talk to your employer to see if this is an option for you. Your loved one's medical team can help you complete the necessary paperwork. For more information about the FMLA visit [www.dol.gov/agencies/whd/fmla](http://www.dol.gov/agencies/whd/fmla)



## FOR MORE INFORMATION VISIT:

American Cancer Society · 800-227-2345 · [www.Cancer.org](http://www.Cancer.org)

CancerCare · 800-813-4673 · [www.CancerCare.org](http://www.CancerCare.org)

Cancer.net · 888-651-3038 · [www.cancer.net](http://www.cancer.net)

Caregiver Action Network · 855-227-3640 · [www.caregiveraction.org](http://www.caregiveraction.org)

Family Caregiver Alliance · 800-445-8106 · [www.caregiver.org](http://www.caregiver.org)

National Alliance for Caregiving · 202-918-1013 · [www.caregiving.org](http://www.caregiving.org)

National Cancer Institute · 800-422-6237 · [www.cancer.gov](http://www.cancer.gov)

Triage Cancer · 424.258.4628 · [www.TriageCancer.org](http://www.TriageCancer.org)

## CANCER SUPPORT COMMUNITY RESOURCES

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-8pm ET and Sat 9am-5pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

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