

Learning about Goals of Care

Information for people living with cancer and
their family caregivers

The EPEC™ Project

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What are Goals of Care?

Goals of Care are a set of personal priorities that can help guide decisions about your cancer treatment and how you live your life.

Setting goals of care takes into account that you are more than your cancer. Cancer may be a large part of your life but there may be other important goals and priorities to consider. Discussing your goals with your loved ones can help them understand your decisions and wishes and help you and your healthcare team make the best treatment decisions for you- and not just your cancer.

You may feel that there are too many decisions to be made or that only your healthcare team can make decisions about your treatment. You have the right to decide your treatment plan and how it will impact your life.

This brochure will teach you:

- ▶ Types of goals
- ▶ Tips for setting goals

Types of Goals

Goals may be different depending on your age, family, values or cancer type. Below are examples of goals of care. It is likely that you will have ones that are specific to you as a person.

LIVESTRONG™ Guidebook. You can also call LIVESTRONG™ SurvivorCare, which can provide you, your family, friends and caregiver with information, education, counseling services and referrals to other resources. They will also help with financial, employment or insurance issues. You can also speak to a case manager Monday - Friday from 9am – 5pm EST.

▶ **American Cancer Society**

1-800-ACS-2345; www.cancer.org

An information specialist can answer your questions 24 hours a day, seven days a week. They can also help you find support groups in your area. The website also has information on talking with your doctor.

▶ **National Coalition for Cancer Survivorship(NCCS)**

1-877-622-7937; www.canceradvocacy.org

As the oldest survivor-led advocacy organization, NCCS is a highly respected authentic voice at the Federal level, advocating for quality cancer care for all Americans and empowering cancer survivors. You can also find information about communicating with your doctor and building a healthcare team on the NCCS website.

▶ **The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning to Talk So Your Doctor Will Listen**

Barbara M. Korsch, Caroline Harding (1997, Oxford)

understands your wishes for support in making treatment decisions.

▶ **Write down your goals**

Tell your friends and family where your goals are written; this will help them find your goals in case of an emergency. Review your progress at each visit and, if needed, make changes to your goals and treatment plan.

▶ **Plan for the best, the worst, and the unexpected**

It is not always possible for your healthcare team to know what will happen next. Make sure that you include goals for unexpected things such as your cancer returning or your treatment not responding as planned.

Resources

The following resources can help you set goals:

▶ **National Cancer Institute – Cancer Information Service**

1-800-4-CANCER; www.cancer.gov

You can speak with caring staff who can explain medical information in easy-to-understand terms. The website also includes multiple resources on coping with cancer.

▶ **Lance Armstrong Foundation (LAF)**

1-866-235-7205; www.livestrong.org

At the LAF website you can read topics about talking to your doctor and order a free

▶ **Living cancer-free**

Your healthcare team can help you set the best and most realistic treatment plan for living free from cancer.

▶ **Living pain-free**

You do not have to suffer from pain. It is very important that you tell your doctor if you have any pain. Your doctor should give you a plan to manage your pain.

▶ **Attending an event or holiday with family or friends**

It may be important to you to travel, or to go to an event such as a wedding or graduation. Changes to your treatment plan may be able to accommodate these goals.

▶ **Having a family**

If you are a young adult, your desire to have a family may influence your treatment plan. This is an important goal to communicate to your healthcare team as some treatments may affect your ability to have children.

▶ **Taking care of your children**

If you have young children, your goals may be to continue to care for them while also making plans for their care if your illness worsens. This may include writing a will laying out your wishes and plans for your children.

► **Leaving a legacy**

It may be important for you to find a special way for your family and friends to remember you, perhaps by writing down or recording your thoughts and memories.

► **Dying with dignity**

For some people with more advanced cancers, dying in a way that meets their needs is very important. Hospice and other palliative care programs can help you to set your end-of-life goals.

Tips for Setting Goals

The following steps can help you set goals for your healthcare based on your own priorities.

► **Agree to be open and honest**

Be open and honest with your healthcare team, family, and yourself. The more honest you are the more likely you are to set meaningful goals and to reach them. These conversations may be difficult because you may have to talk about possibility of death and dying. Patience and understanding are important so that everyone has a chance to discuss their feelings.

► **Talk to your family and friends about your goals**

Your family and friends can help you set meaningful goals. It is helpful to include them as soon as possible in these discussions. They

can offer their own perspectives and emotional support. Even if goals differ these conversations can help your family and friends respect and understand the things that are important to you.

► **Share your goals with your healthcare team**

Talk to your healthcare team about your goals. Your healthcare team should work with you on a treatment plan to meet your goals. They will also help you to understand if it is possible to meet your goals. If you have communicated your goals and you feel your healthcare team is not respecting your wishes, it may be time to get a second opinion. You have the right to select the doctor that will best help you reach your goals.

► **Discuss your goals with your counselor, social worker or spiritual advisor**

It may be helpful to talk to a counselor or spiritual advisor when setting your goals. They can help you decide what is important to you. Your religion or culture may also be very important when deciding what your goals are.

► **Take your time when making decisions about your treatment**

Making decisions about your treatment plan can be emotional and stressful. It may take a long time to decide what you want. When faced with treatment decisions be sure you understand your options and have reviewed your goals of care. It may be important to ask someone who