



# Advanced Care Planning

**B**y now you have probably been told that you have a life threatening or chronic illness, such as cancer, chronic obstructive pulmonary disease (COPD) or heart disease. Chances are treatment has been discussed and planned with you. You likely have heard about the options, benefits, and risks of treatment. You may have a general sense as to what to expect. You may not fully understand the full meaning of this illness; that is okay and normal – it is a journey. Feel free to ask questions. You may be saying “I don’t know what questions to ask.” The following information may offer guidance to you and your family during this difficult time.

### **Ideas to consider: What is important to you?**

- Do you want other people (spouse, family member or friend) to get information about you? Let us know.
- Are you concerned about: Being able to continue to work during treatment? Finances? Insurance? We may be able to help, so be sure to share your concerns.
- Are you starting to feel low or have feelings of persistent sadness? You are not alone; we are here for additional support.
- Are you afraid to ask “what if”? That is normal. You will feel better if you ask. Please talk to us.

As you go through treatment think about what is important to you. Within this framework you may want to consider what your treatment goals are, what is important to you as an individual, and what you value. There are different levels or phases of treatment. Treatment depends on the type of disease and stage of disease.

### **The following is a general description of these phases:**

- Active treatment: Person is diagnosed and begins active involvement in some type of formal treatment.
- Chronic treatment: Person is monitored on a continued basis. They may or may not be receiving treatment. The disease may stay controlled or may progress. People may stay in this phase for a lengthy period of time as an acute illness can often become a chronic and potentially life threatening disease.
- Palliative treatment: Care is given to improve quality of life to a person who has a serious life threatening disease. The focus is on symptom management, pain control, supportive care and decision making related to treatment options.

### **Planning Ahead**

As you go through your journey you may be faced with challenges. Sometimes it is best to plan ahead, so that if a crisis should arise you are not trying to get everything accomplished in a hurried manner. The following is intended to serve as general

information about how you can organize things to reduce stress and worries for you and your loved ones.

- **Advanced directives:** Legal documents that you may prepare ahead of time to allow you to communicate your wishes to family, friends and your healthcare team to avoid confusion later on.
- **Health care proxy:** A type of advance directive that gives a specifically designated person the authority to make healthcare decisions for a patient consistent with the patient's known wishes and values. The proxy becomes active when the patient loses the ability to make and communicate healthcare decisions on his or her own behalf.

Some topics you may wish to discuss with your agent:

- The kind of medical treatment you do and do not want
- How comfortable you wish to be

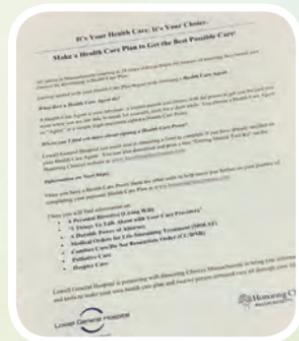
- How you would like people to treat you
- What you would like loved ones to know

Once it is appropriately signed, dated and witnessed it becomes a legal document.

Having a healthcare proxy in place ahead of time provides

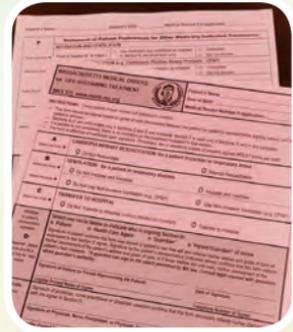
guidance in honoring your wishes. This discussion may also help you and your loved ones define your goals of care, cope with your disease and assist in your well-being.

- **Power of Attorney:** A type of advance directive that gives a person authority to make financial decisions for another person



- **MOLST form (Medical Orders for Life Sustaining Treatment).**

It is intended to be used to honor your wishes regarding medical treatment and quality of life. This form outlines your goals of care based on discussions between you and your healthcare team. Once it is signed and dated this form becomes effective immediately. It can be recognized in a setting outside of a hospital.



**Why are these important?**

If for some reason you are unable to communicate your requests and wishes, you may want someone to be able to speak for you. If you have a healthcare proxy in place, the designated person you have chosen will be able to voice your wishes and honor what you would want done. Sometimes, complications may arise when there is no healthcare proxy in place, especially when a patient's wishes are not readily known.

A Power of Attorney allows someone you trust to gain access to your funds if needed. If for some reason you are incapacitated and cannot access your funds your power of attorney may be activated to assist in management of your financial affairs at that time.

A MOLST form is a way to ensure your own preferences about medical care and end of life care are known and honored. This form, if current and valid, is an order recognized within and outside the hospital, including a home. Each state may have their own form. These forms are recognized outside of a hospital, including a home. These are just a few examples of ways in which you may want to plan ahead. The following pages are other interventions you may wish to discuss with your loved ones and healthcare team. When dealing with a life threatening illness, you may at some point be approached about your hopes and desires for the future. It is important for you to consider your personal treatment goals, your values and your personal threshold for interventions. These are common treatments for sustaining life.

*The following are interventions that may or may not be addressed with you:*



## **Cardio Pulmonary Resuscitation (CPR)**

**What is it?** CPR is done when a person stops breathing or his or her heart stops beating.

**What happens?** During CPR, the chest is pressed on forcefully. Special medicines and electrical stimulation are likely to be used.

**Benefits?** CPR may prolong life for people with a good health status. However, in patients with a life threatening illness, there may be limited benefits in undergoing aggressive life saving measures and should be discussed with your doctor.

**Risks?** Due to the pressing on the chest required, people often have a sore chest, broken ribs or potentially a collapsed lung.

**Is it for me?** It is important for you to consider your values, treatment goals, the stage or progression of your illness and your own personal threshold for treatment. It is important to talk with

your loved ones and healthcare team about what you may or may not want. In most cases, CPR does not reverse the underlying disease process.

### **Artificial Ventilation**

**What is it?** Ventilators are breathing machines which push air and oxygen into the lungs to assist people in breathing.

**What happens?** A tube is inserted down your mouth and throat and into your lungs and then is attached to a machine. A person is usually unable to speak or swallow and may require extra sedation.



**Benefits?** Ventilators may assist in temporarily supporting your lungs so that they may recover and breathe again on their own.

**Risks?** There may be discomfort, although people are usually given extra medication to keep them comfortable. A person

can become dependent on a ventilator if their lungs are unable to function again.

***Is it for me?*** It is important for you to evaluate your wishes. Sometimes a ventilator is used on a temporary basis; however, ventilators do not reverse the disease process. Discussing your personal treatment goals will help you decide and direct what the goals of treatment are.

Whether you have just been diagnosed with a life threatening illness or have been dealing with the illness for many years, there are many decisions that you may have to face. One such issue is the topic of code status. During any stage of an illness you may be asked about your wishes for code status. What this refers to is the procedures that can be performed if your heart were to stop or if your lungs were to fail.

**You may be asked the following:**

*If your heart were to stop would you want CPR performed to try to restore heart functioning?*

*If your lungs were to fail, would do you want to be connected to a breathing machine?*

If your answer is **YES** to both of these interventions then your healthcare team will talk to you about being a full code. This means that all measures will be taken to keep you alive.

If your answer is **NO** to both of the above interventions then your healthcare team will talk to you about being classified as a **DNR/DNI-Do Not Resuscitate/Do Not Intubate**. This means that you would not want any extraordinary measures or procedures done to you. This does not mean that you would not be kept comfortable and be given pain relief. If you decide to make yourself a DNR/DNI you would still receive medical treatment as deemed appropriate by your treating MD.

Another way people are now looking at DNR/DNI status is they are referring to it as an AND – Allowing Natural Death. This means that measures are taken to keep a person comfortable and he or she dies in a natural manner. Focus may be placed on care and comfort measures if a person is at the end stage of an illness. Again, your treatment goals help determine the direction of your care.

Your permission is needed before a physician, nurse practitioner, or physician assistant can write a DNR/DNI order on your behalf. You may be asked to sign this form confirming your wishes. This decision would not impact the physician's role to keep you or your loved one comfortable and provide pain relief.



## Feeding Tubes

**What is it?** A feeding tube may provide nutrition to people who may have difficulty swallowing or are unable to eat for medical reasons.

**What happens?** There are different types of feeding

tubes and consideration is given as to which one may best benefit an individual before placement. It may be inserted into the stomach (G tube); through the nose and into the stomach (NG tube) or into the small intestine (J tube).

**Benefits?** It may provide nutrition and aid in the process of eating during treatment. Feeding tubes are recommended to best support a patient during his/her treatment, for certain types of life threatening illnesses.

**Risks?** If you have an advanced disease you may be providing your body with foods and liquids. This may be extending your life in a manner beyond what you desire.

**Is it for me?** It may be important for you to discuss the role and purpose of the feeding tube. Most people choose not to be kept alive by a feeding tube if their quality of life would be poor; however, this is a personal decision and one that you may wish to discuss with your loved ones and healthcare team.

### **Continuum of Care**

During a serious illness, focus on treatment and goals of care are likely to change. As your wishes change, care available to you also changes. Below are some services available to you.

### **Palliative Care**

What is it? Palliative care is focused on overall quality of life for people with a serious illness. Its focus is on symptom and pain management and supportive measures. People may continue with treatment, remain active with their care team and receive home assistance. It can be offered at any time during a chronic

illness and help people live with dignity while allowing your values, wishes and goals to match your plan of care.



### **Hospice Care**

***What is it?*** Hospice care is focused on compassionate care and comfort measures, not a cure, at the end of one's life. It is an option for care when treatment is no longer helpful and life expectancy

may be six months or less. The focus is on comfort and dignity, pain management and quality of life. Support is available to you and your loved ones during hospice care and for one year after a person's passing. Focusing on care and comfort measures and dying a good death is obtainable. Knowing what you value does play an important role in obtaining this goal.

Expectations and hope for good quality care runs the continuum of treatment. A patient's disease may change pending their response to treatment and options for care may be an ongoing discussion.

In conclusion, whatever phase of treatment you may be in, we encourage active discussion. Whether one looks for a cure, maintenance or improvement in functioning, prolongation of life, relief of suffering, quality of life, or a good death, open communication of your wishes will only help you and your loved ones. By letting your healthcare team know your goals, it will give the best direction for your treatment and care. We hope this pamphlet will help you through your journey.

Thank you for allowing us the privilege to walk this journey alongside you.

