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Hospice & Home Support  
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Winter 2015 Information and Resources

# Difficult, Important Conversations Making your wishes known

by Elizabeth Landrum, PhD

It usually seems that there is never a "good time" to talk about death and dying. Difficult conversations are easy to avoid or postpone, and often, even talking of dying can be viewed as somehow stealing from life or bringing death quicker. But words won't hurry death, and, since most of us want the assurance that our wishes are known and followed when the time comes, these can be some of the most important conversations we have.

With so much in the news about our aging population and end-of-life care, people are paying more attention to their personal ideas about how they would want to face death and to be treated at the end of life. Still, their families and physicians usually do not know their choices when they most need to know. **Communication** is the single most important step in advance care planning, yet we are ill prepared for how to begin and continue these important conversations. Efforts are being made on varied fronts to facilitate these talks, from requiring health insurance to reimburse physicians for end-of-life discussions with patients, to websites like the Conversation Project ([www.theconversationproject.org](http://www.theconversationproject.org)), offering tools, resources and guidance in how to talk with loved ones.

We **need not wait** for a tragedy to anticipate what decisions might need to be made in a time of crisis.

In fact, opening a conversation about incapacity and death can be easier when it is more theoretical. Sudden changes in health and physical status can happen, even to the young and healthy, sometimes forcing others to make difficult decisions about life-sustaining treatments. It isn't too early, but it can be too late, to discuss your wishes.

When a person communicates their preferences ahead of time, it **decreases the chances of future conflict and confusion and reduces the burden on the family.** The sense of control and **peace of mind** this process fosters in the individual and the reduction of stress for decision makers are immeasurable. When it comes time to make important end-of-life decisions, about 50% of people are incapable of making them. And when health professionals are uncertain about what decisions to make, their default will be to treat. This can sometimes result in unwanted, prolonged treatment or institutional care; asking to remove a medical device or treatment for someone else is often more emotionally difficult than declining it initially.

Making your wishes known is a process that can be complicated, involving a variety of legal, medical and financial decisions. It should take place over **several conversations, beginning with general values and goals**, not with specific medical choices. You might want to discuss your particular experiences, as these always influence your values, beliefs and fears which, in turn, shape your preferences. The process may involve writing your values and desires, or formalizing advanced directives such as a Living Will, Durable Power of Attorney

## Difficult, Important Conversations, con't.

for Health Care or Physicians Orders for Life-Sustaining Treatment, but not necessarily and not immediately.

It is always important to **identify the person** or people you choose to make decisions for you when you cannot, and to **let them know** what sorts of decisions you prefer. And when you have designated a health care proxy, be sure to let everyone concerned know who it is and where to find your advance directives. (see Notes)

A **three-step process** is recommended, starting with basic planning when you are healthy, reconsidering your wishes if you are diagnosed with a serious illness, and becoming more precise if you realize you may be approaching the final stages of life. As your wishes and goals are likely to change, you will need to **revisit, reconsider, and revise** periodically. Don't avoid re-opening conversations, and even documents, with your loved ones and health care providers.

Beginning the conversation can be tension-filled, so choose a **comfortable, safe and unhurried setting**. Storytelling can be a good way to break the ice, possibly one you know personally or read about or saw in a movie. It can also be helpful to ask your family for their help as you're thinking of the future, and to begin with "what if" rather than "when." Sharing your own personal concerns, values, spiritual beliefs or views about what makes life worth living might be helpful conversation starters.

People have differing tolerances for sensitive, philosophical, or medical conversations, so watch for cues and allow for breaks. **Be patient**, and consider every attempt and every talk to be beneficial. Sometimes, clear thoughts about these issues and certainty of one's desires can arise only by **taking time**. If early conversations go well, later ones will be easier. Because exchanges about end-of-life issues are emotionally charged, paying attention to all feelings associated with the content will be valuable. Deeper understandings of hopes and fears surrounding illness and dying can come

from asking **open-ended questions** (see below), making **empathetic responses**, understanding differences, and fostering **acceptance**.

Whether it is to give you **a voice in your care** should you be unable to speak for yourself, or so that you might **understand what your loved ones want** when you have to respond, Lopez Island Hospice and Home Support hopes to provide help in overcoming the barriers to having these frank discussions. Watch for future community programs on these issues.

### Notes:

*Advance directives help you state your choices for receiving medical care in advance of a serious illness or a health crisis. There are many legal considerations when formalizing advance directives. Several online resources provide information about, and forms for, advance directives, including [www.caringinfo.org](http://www.caringinfo.org), [www.hospicefoundation.org](http://www.hospicefoundation.org), and [www.compassionWA.org](http://www.compassionWA.org).*

*The Five Wishes form is a copyrighted "ethical will" which is legally valid in Washington. It can be accessed on the website [www.agingwithdignity.org](http://www.agingwithdignity.org) and is also available (in English or Spanish) in the LIHHS office by request.*

## Values Clarifications - Questions to ask

Even if you have signed advanced directives, they can be difficult to interpret in a specific medical situation. Since we can't predict the details, having values discussions can be as important as legal documents. Understanding what is important to you can guide and comfort those who might be asked to make decisions for you.

Here are some questions that might help to guide your discussions over time:

- What do you value most in your life? What does "quality of life" mean to you?
- What reactions have you had to other people's stories of end-of-life?
- What experiences with death and dying have influenced you?
- What is most important to you when you think of your last phase of life?

## Values Clarification, con't.

- What are your greatest concerns or fears about the last phase of life? Your hopes?
- Who do you want (or don't want) to be involved in your care?
- What disagreements or tensions among family or loved ones would you be concerned about and how would you want to minimize them?
- What circumstances would you consider to be worse than death?
- What kinds of mental and physical conditions would make you think life-prolonging treatment should no longer be used?
- Under what conditions could you imagine temporarily accepting medical treatment?
- When would it be OK to shift from curative to comfort care alone?
- What religious or moral values do you hold that should be understood by caregivers?
- Where would you want to receive care? How would you want to be cared for?
- What wishes do you have for arrangements after your death?



## New Cancer Support Group Offered

Lopez Island Hospice & Home Support is now offering a free, open support group for anyone living with cancer.

Scientific evidence is growing that people who participate in cancer support groups actually fare better than those who don't, in terms of both quality and quantity of life. This group meeting is designed to create a safe, confidential space and time for sharing thoughts and feelings with others, and it will include opportunities for examining life values and goals, as well as ideas for improving coping strategies.

The group is facilitated by Elizabeth Landrum, a retired clinical psychologist, and meets at the Hospice & Home Support office on the second and fourth Tuesdays of each month from 3:00 to 4:30 p.m. Drop-ins are welcome. For further information, call 468-4446.

## Have You Thought About This?

*Advance planning isn't just about health care directives and wills...*

After her husband died in a bicycle accident near Lake Washington, Chanel Reynolds was overwhelmed with the unfinished tasks and disorganization that made her grief much more difficult. So she developed a website called "getyourshittogether.org." It's designed to alleviate the *unnecessary* suffering that comes with sudden serious illness, accident, or death. It includes checklists and toolkits to help people organize and plan in order to make overwhelming tasks easier for those who must take over. Some of her suggestions are useful for all of us as we consider what would happen if we were suddenly incapacitated. Simply having a file containing important information could make life so much easier for your friends and loved ones. So tell someone where to find your "In Case of Emergency or Death" file, and don't forget to update your information at least every year.

### Information should include:

- Contact information (phone numbers) for all emergency contacts. Include your primary care physician. This is important information to leave visible for emergency responders.
- Medical alerts, conditions, and allergies.
- Durable Powers of Attorney for health care and finances.

### Where to find:

- Social Security number, birth and marriage certificates.
- Medical insurance and physicians' names.
- Bank accounts and financial institutions.
- Autopay accounts.
- Will.
- Insurance policies: car, home, life, disability.
- Computer username and password.
- Important keys: house, cars, safe deposit boxes, files.
- Pet instructions.



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## Winter 2015 Information and Resources

### ***Jingle Bell Dinner a Great Success***

Thanks to our sponsors, guests, and volunteers, the 2014 Jingle Bell Dinner was a great success! With exciting auction items, entertainment by Robert Herrmann, stunning centerpieces by Debbie Collins, and a fabulous dinner provided by The Bay, a good time was definitely had by all.

The generosity of our community made for an amazing evening. The event brought in more than \$25,000 to assist Lopez Island Hospice & Home Support in helping our neighbors in need.

Thanks once again for your support and dedication to Lopez Island Hospice & Home Support.

### ***Welcome to New Board Members***

On January 19, 2015, three new members were elected to the Lopez Island Hospice & Home Support Board of Directors.

**Judy Dern** – 3rd generation Lopezian living here full-time for the past year. BSN from the University of Washington. Worked as a community hospice nurse/case manager in the Portland, Oregon area.

**Nancy Ewert** – MA Rehabilitation Counseling with specialty in Spinal Cord injuries. Early Childhood Parent educator through Skagit Valley College for Lopez preschool.

**Connie Harris** – Bachelor of Arts from Central Washington University. Member of the Lopez Community Center Home Tour Committee for the past eleven years. Full time citizen on Lopez for 18 years.

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