

## “Reclaiming Your Life After Cancer”

Lopez Hospice and Home Support is sponsoring a community program, “Reclaiming your Life,” Saturday, September 27, 2pm at the Gathering Place in the Lopez Hamlet. Kathleen Albin, M.A., is offering a workshop about living with cancer. She is a licensed mental health counselor specializing in individual and group counseling for grief, traumatic loss, and terminal illness. This program will be relevant to those living with cancer, their loved ones, and any other interested people.

An 8-week educational support group for people living with a diagnosis of any type of cancer will be starting in October. If you are interested in joining the group or in gathering more information, please call 468-4446.



*Many of the stories in this summer’s newsletter have supporting links on the web which we have listed on our own website, lihhs.org. We hope it makes it easier to access the information on line. If you have questions, please call the office at 468-4446.*



“Oh, my friend, it’s not what they take away from you that counts - it’s what you do with what you have left.”

*Hubert Humphrey, after cancer surgery in 1978*

## Changes in Medicare Hospice Regulations

In certain participating hospice programs, Medicare and Medicaid patients will be able to receive medical treatment and hospice treatment at the same time, enabling patients to access palliative care while still in treatment. The Medicare Choices Model is a program designed under the Affordable Care Act to test improvements in quality of life of patients receiving both curative and palliative care. This study could lead to important changes in hospice insurance regulations and may allow earlier access to hospice.

In another new ruling, those people who are not showing marked improvement in their condition by being in a facility (Alzheimer’s, stroke, etc.) may have their stay covered by Medicare.

If you have questions, please contact Mary O’Bryant at 468-2421.

## When Planning Makes a Difference

Did you know?

90% of people think it is important to talk about their loved ones’ and their own wishes for end of life care, BUT less than 30% have done so. 82% say it is important to put their wishes in writing, BUT 23% have actually done it.

Because most people find that discussing end-of-life preferences is difficult to do and easy to postpone (often until it is too late), and because having a clear understanding of an individual’s preferences can make huge differences in choices and care at a critical and emotional time, Lopez Island Hospice & Home Support is committed to assisting in advanced planning for our community.

We are offering the first in a series of discussions on October 18 when Attorney Cy Field will be talking about the legal aspects of advanced directives.

If you have questions about this important discussion, please contact the office or go to [www.lihhs.org](http://www.lihhs.org).

## Web Sites Can Make Life Easier

You or a family member has a serious condition. You're seeing specialists off island, arranging care, organizing meals, and taking care of the myriad details that go along with serious disease. People want to know how things are going, but sometimes just answering the phone can be a challenge.

*Caring Bridge* is a non-profit organization that provides a personal website where you can discuss your condition, day to day status, and give your loved ones a safe, private place to leave messages of hope and caring. *Caring Bridge* allows frequent visitors and well wishers to stay connected, no matter the time or place.

*Lotsa Helping Hands* is a web service connecting those in need with friends and acquaintances who want to provide rides and meals, do chores or pay visits. It coordinates assistance, and enables you to create an on-line community of caring.

Nancy Ewert knows the benefits of a site on the web: "*Caring Bridge* was a lifeline for me and for our family. Greg's illness required so much of us at certain times that communication by "normal" means was just not possible. Using it helped us share our experience and receive support that sustained us in profound ways. We were constantly buoyed up by messages we received from friends near and afar. I don't know how we would have made it through without it."

Jennell Kvistad took advantage of *Caring Bridge* when she was diagnosed with breast cancer and wanted to share her family's journey. "It offered me a way to engage with my community, near and far, about the trials and triumphs of my dance with cancer. It offered my friends and family a way to show their support all in one place so as not to overwhelm me with one-on-one communications. Most importantly, it offered me a forum to creatively express my thoughts and feelings during an incredibly tumultuous time."

*Caring Bridge* and *Lotsa Helping Hands* are just two web-based services that have provided Lopezians other ways to share. Find more on [lihhs.org](http://lihhs.org).

## Moving Into The Digital Age

Lopez Island Hospice & Home Support has joined the digital age. You can now make a donation on our web site at [www.lihhs.org](http://www.lihhs.org). Click on the Donate button: If you want to write and mail a check, you can download and print a form. Or you can click on the PayPal line; here you can donate via their secure portal with a PayPal card if you have one, or you can scroll to the bottom of the screen to use a VISA or MasterCard.

If you spend lots of time (and money) on Amazon, you can sign up to donate .5% of your purchase cost. Just Google <http://smile.amazon.com/> and type Lopez Island Hospice And Home Support into the search field. NOTE: Be sure to use the word "and," not the ampersand.

Half a percent may not sound like much, but just think about how many times you go to Amazon to purchase an item. Many on line companies are offering this opportunity to support customers' favorite nonprofit organizations. It's good advertising for the company, and a win for the nonprofit as well.

Lopez Island Hospice & Home Support operates entirely on donations and some local grants; larger grant-funding groups typically don't provide funds for operations and maintenance. As a mostly-volunteer nonprofit, most of our costs are in these areas, so we are always looking for ways to make it easy and satisfying for our supporters to donate.



"Dealing with it is the operative word. I found myself at seven years not battling it. Not suffering from it. Not struggling with it. Not breaking under the burden of it, but dealing with it."

*Michael J. Fox, referring to his Parkinson's Disease in a Barbera Walters interview in 1998*



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***Save the date for the Jingle Bell Dinner!***

Bring out your sparklies and your holiday sweaters, your festive ties and those Christmas pins...it's just about time to party!

Mark your calendar for November 29th for the 6th Annual Lopez Island Hospice & Home Support Jingle Bell Dinner. Catered by The Bay, the Jingle Bell Dinner is our major fundraiser of the year, and gives you an opportunity to give and have fun at the same time. Last year we brought in over \$28,000, which was a record for the event. Will you help us top it this year?

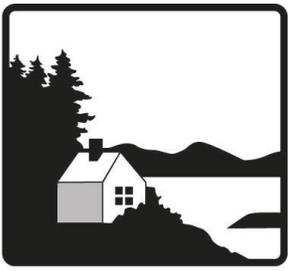
Tickets go on sale October 7th. Last year we sold out, so purchase your tickets early.

***Welcome to New Board Members***

Please welcome our hardworking new board members.

Kathleen Pallansch worked as a registered nurse in the Seattle area for more than 35 years, primarily in oncology, bone marrow transplant, and AIDS. She moved to Lopez in 2012 with her husband Patrick. She has two daughters (Mariah and Claire), and two golden retrievers.

Tom Ruggles and his wife Gayle have been property owners on Lopez Island since 2000, and four months ago became full time Lopezians. He is a retired banker specializing in small business lending, and worked in the industry for 20 years.



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Hospice & Home Support  
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Summer 2014 Information and Resources

# After Cancer Treatment - Now What?

by Elizabeth Landrum, PhD, Board Chair

In the beginning, people diagnosed with cancer often feel like the fabled Dorothy whose house was catapulted by a tornado into a strange land where nothing is familiar and little makes sense. More questions than answers seem to surface. Treatment options are taken, declined, and negotiated, often with a team of professionals watching closely, and new skills are developed to cope with the new world.

When cancer treatment ends, another new chapter begins. This can be a time of relief, celebration, and hope, yet many people recovering from treatment are surprised to find it is also a time of sadness, fear, and feeling lost. The reduction of an actively engaged treatment team can feel like losing a safety net. Since it is human nature to want to maintain a sense of control, even when control is not in our hands, people often want something to do to manage their disease. Militaristic language and images often used with cancer might wrongly imply that, if one is not "fighting," there must then be victory, surrender, or defeat.

Yet the true challenge may be to learn to live with the physical and emotional effects of cancer on a day to day basis. For many, it's about living with cancer as a chronic disease. Fears about what lies ahead are nearly universal; definitions of hope will probably need to be reconstructed, perhaps many times during the cancer journey.

As cancer affects one's physical health, it also changes the ways a

person feels, thinks, functions in the world, and views life. Adapting to a "new normal" makes more sense than going "back to normal." Integrating what has happened, finding acceptance for what is, and adapting to so much change can take a long time. People will need to understand what having cancer means to their life now and to allow for continuing discoveries over time. With less focus on the next appointments, symptoms, and medical questions, grief for what has been lost often surfaces. Social support may diminish as the crisis appears to have passed. This is a time for dealing with changes in the patterns of important relationships, as well as with changes in beliefs and perspectives.

Setting new goals and priorities can be helpful in navigating this chapter; "coping well" might mean focusing on both healing and wellness. This is an opportune time for choosing among many complementary therapies (e.g. meditation, yoga, nutrition, massage, imagery), as well as for physical and creative outlets. A support group can promote healing and peace by telling and hearing stories about living with cancer, the aftereffects of treatment, about personal and interpersonal changes, by sharing coping strategies, and just having a place to air one's concerns.

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*The challenges of cancer are great. We at Lopez Island Hospice & Home Support hope the information in this newsletter will provide some help as you continue your journey.*

# When Someone You Know Has Cancer

by Nancy Ewert and Elizabeth Landrum

With over 12 million people in the U.S. living with cancer today, chances are you know someone who has cancer. Feeling insecure or confused about how to communicate with that person is common. This discomfort can lead to avoidance, awkwardness, intrusiveness, and/or regret. Saying or doing the “wrong” thing can take on emotional significance for either party at the most stressful of times. Although one often doesn’t know what to say, one can **make room for forgiveness** (of ourselves and others), knowing that motivations come from caring, and that well-meaning people will stumble at times.

The following ideas come from the experiences of cancer patients and their families. On a small island such as ours, news travels fast; people care about and want to help others in difficult times. We hope these suggestions will be beneficial.

**Allow the person and their closest loved ones time** to digest the initial shock that comes with a diagnosis of cancer. Initially, they will be disoriented and overwhelmed by emotions, decisions, information, and appointments. Remember that, even when you see them, you cannot see their internal experience. They may be making life and death decisions while trying to appear OK and carry on with the demands of everyday life.

**Expect them to have good and bad days**, so don’t expect yourself to be able to know how they will feel at any particular time.

Remember that cancer is a disease that profoundly affects the whole family. If you are asking about the patient, you might ask about their closest others as well.

**Take your cues from the person.** It is natural for interpersonal contact to be difficult when dealing with a diagnosis or treatment. Try not to take it personally. Respect their need to share and/or their need for privacy, and avoid being intrusive with your questions or comments.

**Let them know you are willing to listen** IF you can listen with an open heart. Because you don’t want to ignore them, turn away, or pretend to not know what you know, keep in mind that the simplest expressions of concern are the most meaningful. A caring look or a nod, and sometimes a touch, are often remembered when words are forgotten. Authenticity is usually perceptible.

**Respond from the heart.** “I’m not sure what to say but I want you to know I care” or “I’ll keep you in my thoughts” will communicate your support. A simple note, with no expectation of a response, is often appreciated. People do feel and need the support that surrounds them. Messages on a site like *Caring Bridge* (see page 5) can be read in the person’s own time and can mean a great deal when that time is right.

**Try to avoid platitudes** (which may not be true) such as “Everything will be all right” or “I know how you feel” or “You must think positively”.

**It is better not to ask what you can do to help**, as it might not be possible for the person to think of what is needed or how to make assignments. Instead, **offer to assist with or to do a specific thing**, such as doing laundry, paying for housekeeping, or mowing the lawn. Tasks you can do without requiring direction or energy from the family will be most helpful. Sometimes coordinating help, like the delivery of meals, can be aided by on-line organizers like *Lotsa Helping Hands* (see page 5).

When someone is having a test or significant appointment, they may need time to process what they have learned. Remember that public places are rarely environments conducive to sharing personal information. **Trust the person and family to decide how they want to disseminate information.** They may choose to use the internet or another friend as sources of information to save their energies for each other and for healing.

# When Someone You Know Has Cancer

*continued from other side*

**Try to avoid comparing or sharing other stories about cancer**, stories of survival, treatments or stories of death. Every cancer is unique. If you want them to know you have relevant experience to share, ask if it is wanted. The patient and family are probably overwhelmed with information already. **Be sensitive to their needs.** Advice, readings, or suggestions for treatment alternatives can all feel burdensome.

Because there will always be well-intentioned people who want to share hopeful solutions and information, a point person to manage the incoming information can be extremely helpful. Either offer to be that person (be willing to receive emails with web links and calls) or honor requests to share information and resources only through that person. Positive thinking, alternative therapies and particular diets may or may not contribute to healing and are also deeply personal decisions. **Have respect for their process** of gathering information and consulting experts of their choosing, **as well as their decisions.** Be mindful of how important it is for people to maintain faith in their own choices.

Questions or statements about risk factors such as smoking, poor diet, environmental exposures, or stress might arise from a desire for explanation, yet they can be construed as blame. Remember that cancer's causes are complex, numerous, and not well-understood.

**It is best not to focus on how people look**, whether it is sick, healthy, or improved. They might be self-conscious and not want to call attention to how they appear.

Since the person living with cancer wants to be seen as a whole person and not just as a cancer patient, offer the gift of reminders of their strengths, interests, and parts that have nothing to do with cancer. Reflect on enjoyable times spent together. **Include and encourage them in normal activities**, and be available for the ways you related before cancer entered the picture. Be sure to ask

what they feel like doing, as they will need to decide about how to expend their limited energy. Continuing to feel like an active and contributing individual may provide a sense of meaning, confidence, and control.

You might be very important in their journey, but **don't assume you will be a confidante** just because you have a lot to give. If you were not intimate before the diagnosis, you probably won't be afterwards. Avoid over-interpreting their need to retreat.

Remember that **support is important throughout the cancer journey.** Some people are best at crisis response ("firefighters"), and others may be better equipped to hang in for the long term, no matter what comes ("builders"). You don't need to be able to do it all. Since people with cancer and their families sometimes feel abandoned after the initial diagnosis and treatment, remember that caring responses will be appreciated for a long time to come. Dealing with cancer usually means discovering who real friends are.

If you have deep feelings about their situation, be honest, but try not to put them in a position where they have to console you. This may mean that you need to find other outlets for your own distress, fear, and grief.

When the person with cancer or their loved ones want to talk openly, let them take the lead. **Be willing to listen to any and all emotions** and concerns expressed without judgment, attempts to change how they feel, or your need to offer a positive spin. **Give your understanding, support and encouragement**, knowing it is compassion for their feelings that is needed. **Be willing to sit with silence and uncomfortable moments.**

**Never underestimate the power of a caring, calm presence.** Deep listening can be the greatest gift you can give. Let your words and actions come from your heart, and don't worry about doing everything perfectly.