



The Most Difficult Decision When to call Hospice

by Nancy Ewert

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Lopez Island
Hospice & Home Support
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All services are free.

When my husband was diagnosed with brain cancer in 2010, I knew we would eventually need end of life care. Glioblastoma is almost always fatal within two years, and I knew that so we had no illusions. Our family made a commitment to Greg and each other that we would take care of him at home – in the home we built ourselves on Lopez, in the home where our three children were raised, in the home that nurtured our dreams...in the home that Greg loved.

It was one of the most difficult calls I ever had to make.

During the months prior to Greg's diagnosis, I had read an article by Atul Gawande, in which he related how most families facing the death of a loved one do not call hospice until a crisis has arisen and the family is desperate, often within days of a death. At that point, the services that hospice can offer are limited, there is little opportunity to develop a personal relationship with the care team, and the family often misses the opportunity to embrace the dying process in a less stressful manner.

Despite my knowledge and some personal experiences with the dying process, my eventual call to Hospice of the Northwest (HNW) was one of the most difficult calls I ever had to

make. To this day, I remember where I was sitting, the voice of the person I talked to, and how I spoke quietly so no one in the house could hear me, even though we all agreed it was time to call.

Given this set of circumstances, one might think that I, of all people, would be ready to call hospice and ask for services. As I reflect on this time, I suppose it was an admission of finality, of facing the reality I thought I had already faced.

Greg was still receiving treatment that was considered "curative," so our first meeting in our home with a nurse from HNW was for informational purposes. After this two hour meeting, which gave us a full picture of the wide range of services available to us even on Lopez Island,

I needed the support to think through the "what ifs" of our ever changing reality.

Greg decided it was time to stop the treatment which did not appear to be slowing the growth of his tumor. He chose quality of life with hospice over grueling, repeated trips to the mainland with no real relationship with a healthcare team. Because we arranged for these services early, we were able to explore what quality

The Most Difficult Decision, con't.

of life meant to Greg and develop a meaningful relationship with the staff of HNW.

To our surprise, one of our first meetings with the HNW nurse in our home included his assistance and encouragement to take a family trip to Hawaii - a trip that Greg really wanted. I needed the support and planning to think through the "what ifs." We took with us the equipment borrowed from Lopez Island Hospice & Home Support, and we had the assurance that we could call HNW and if needed, they could contact a hospice agency on Maui to help us.

We gave ourselves the rare family gift of assisting our loved one with deep love, tenderness, and care, thanks to hospice.

As Greg's disease progressed over the next six months, the assistance from HNW was essential to fulfill our desire for Greg to spend this time in the home and community he loved. There were weekly nursing visits that we always looked forward to. Later, there were weekly baths, and a hospital bed was delivered to our home as soon as we determined it was necessary. Most importantly, there were many heart-to-heart talks among all of our family members with the HNW nurse about what was happening, what to expect, and how to help. The occasional frantic phone calls from me were always met with compassionate and skillful assistance from our nurse or the 24-hour on-call nursing staff.

I am grateful that I knew to call before a crisis occurred, AND I will not deny that it felt at the time like maybe we were "giving up." Instead, we were giving ourselves the rare family gift of assisting our loved one into the inevitable transition we all face one day with deep love, tenderness, and care.

Sooner Rather than Later

by Mary O'Bryant, Client Services Manager

"My friends and family keep telling me: 'Call Mary.' I admit that I have put them off. I wanted to wait until I was sure I really needed help before I made the call." As case manager for Lopez Island Hospice and Home Support, this is the opening of many of the calls I get asking for help. The caregiver then proceeds to describe that he/she is totally overwhelmed. "I can't get away from the house at all, and I have no time to myself. It would be so good to have two or three hours each week when I didn't need to worry about my loved one. "I am often told: "I live alone; I am unsteady on my feet; it is difficult for me to do things around the house; I would like to go to the market and the pharmacy, but I can't drive." I might hear: "My spouse is dying; I would like to just take a walk or a nap and know that he/she is not alone."

Sometimes a call for help follows a crisis, and more troubles follow, including ones that might have been prevented by planning ahead.

We have all heard that in order to take care of others, we first need to take care of ourselves. However, "our self" is the first person we ignore and continue to ignore when we are in the role of caregiver.

If you call me, I can explain what Lopez Hospice and Home Support offers, including one or more volunteers who might visit each week to provide support and/or tasks for you and your loved one. That is why we are here. The sooner you call, the sooner you will receive support and lessen the chances of feeling overwhelmed, exhausted, and responding in crisis mode.

Don't wait. Call 468-4446 sooner rather than later for information or assistance.



"The best way to find yourself is to lose yourself in the service of others."

***Being Mortal* an Important Read**

by Ginger Lowell

Atul Gawande is a surgeon. In his best-selling book, *Being Mortal*, Dr. Gawande's journey is told through stories of his patients' travels toward the end of life

In medical school he was taught to cure people - to diagnose their medical problems, research the symptoms, and develop a course of action that results in a cure. But there is no cure for death. And there are no cures for many of the illnesses and injuries people experience. Dr. Gawande ponders this period of time - days, months, years - during which he travels with his patients on their journeys through life. As he travels, he discerns three stages of his own. The first is the doctor's objective: define the problem, develop a course of treatment, and cure. In this stage, the doctor is playing God; the patient is a supplicant, not a participant in his own future. In the second stage, the doctor is more open with the patient, explaining the likely course of the disease or injury recovery, possible treatments, and asking the patient to make choices. Still, Dr. Gawande realizes, the doctor is controlling the choices among the several ways to die. Finally, the doctor realizes that what most people want when facing decline and death is to feel that they are in control of their quality of life.

Recognizing the importance of honoring each person's wishes and acting in ways that support those individualities is upside-down thinking for doctors who are trained to cure, family members who are constrained by social, cultural, or religious tenets, or for bureaucracies that provide a set of services in which one size fits all. We all have our own ways of living, and it's no different when we face death. Dr. Gawande knows he's reached that third stage when he asks his patients what it is that will make them happy as they move toward death, and tailors his medical advice to support that process.

Being Mortal, by Atul Gawande. Metropolitan Books/Henry Holt and Co., 2014

Volunteer Opportunities with LIHHS

"We make a living by what we get, but we make a life by what we give."

- Winston Churchill

Are you asking yourself what important things you could be working on right now? Have you thought about volunteering?

Volunteering is not just about giving. Research shows that life expectancy is higher for people who volunteer. Perhaps the inherent satisfaction bolsters our immune systems in some way. Important life lessons can be gleaned from volunteering with Lopez Island Hospice & Home Support, including a healthy perspective on what is truly important, the benefits of nourishing relationships, and opportunities to learn from our clients in unexpected ways.

Our volunteer training course includes valuable information about what people need who are ill, grieving or dying, how to be a caring presence with others in need, communication and bereavement skills, and self-awareness. Volunteers who have participated in past classes have said they are some of the most valuable learning experiences they've had. Many have felt the benefits reach far beyond their volunteer work, enhancing their personal lives, and allowing them to feel much more comfortable and confident in difficult or unfamiliar situations.

LIHHS is currently accepting applications for volunteers, and is making plans for an extended training program in February and March of 2016. These classes are required of our direct care volunteers and are offered only every three years, so please consider signing up now. Call 468-4446 for more information or to request an application. The application is also available on our website, lihhs.org



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Summer 2015 Information and Resources

Jingle Bell Dinner November 28

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

Mark November 28th on your calendar for the Annual Lopez Island Hospice & Home Support Jingle Bell Dinner. The Jingle Bell Dinner is our major fundraiser of the year, and gives you an opportunity to support our Lopez Island neighbors and have fun at the same time.

This year we'll have a special treat and a lot of laughs - we'll be joined by Jet City Improv, one of Seattle's longest running improv groups.

Join us for a Lopez Island tradition - the Jingle Bell Dinner. Tickets go on sale early in October. Last year we sold out, so get your tickets early.

Resources for Living Long on Lopez

If you've found the information on the various hospice and home support resources on Lopez of value, mark your calendar for a panel discussion on Sunday, October 18th.

"Resources for Living Long on Lopez: Whom to Call and When to Call" is your opportunity to ask questions of people in the know: representatives from Lopez Island Hospice and Home Support, Hospice of the Northwest, experts in palliative care, and the Lopez Island Family Resource Center.

Look for announcements for time and place.

For more information, please call the office at 468-4446, or go to our website, lihhs.org

Frequently Asked Questions about Lopez Island Hospice, & Home Support, Hospice of the Northwest, and Palliative Care Services

In an effort to answer some of the questions we often encounter about different local hospice organizations and services available on Lopez Island, here are a few brief answers as a starting point.

What is Hospice care?

Hospice is a philosophy of care that values quality of life and empowerment of people, supporting their choices in how they live and maintain dignity, as well as compassionate care to make a limited life as comfortable and meaningful as possible. Hospice care involves the patient as well as family and caregivers in making individualized plans centered on the individual's comfort, goals, needs, and beliefs. These are philosophies shared by Lopez Island Hospice and Home Support (LIHHS), Hospice of the Northwest (HNW), and close to 6,000 hospice programs nationwide.

What is Lopez Island Hospice & Home Support (LIHHS)?

LIHHS is a skilled volunteer organization providing confidential, quality, no-cost, non-medical hospice and home support services and resources to the Lopez community experiencing illness, injury and/or loss at any stage of life.

Who qualifies, and how, for LIHHS services?

Services from LIHHS may be requested by any Lopez resident with an illness (not necessarily terminal), injury, or major loss. The Client Services Manager will assess the person's needs and decide if our services are appropriate. We will evaluate the client's desires, expectations and goals, make a plan, and suggest possible resources, assigning LIHHS volunteers as necessary. This professional assessment is free and confidential.

What is Hospice of the Northwest (HNW), formerly Skagit Hospice Services?

HNW is a skilled team of nursing, medical, social and spiritual professionals and volunteers who provide comprehensive care and comfort for people with life-limiting illness in Skagit, Island, San Juan, and Snohomish counties. Based in Mt. Vernon, they offer a range of services designed to ease symptoms and difficulties associated with late-stage illness. Services include regular visits from the entire team, 24-hour telephone nurse support, related medications, oxygen, hospital beds and other durable medical equipment, education, spiritual and bereavement support.

Who qualifies, and how, for HNW services?

A person can be referred to HNW by anyone, but for insurance or Medicare to pay for the service it must be ordered by a physician. To qualify for services, a face-to-face assessment by a doctor must determine that there is reason to believe that the patient may have a life expectancy of six months or less.

Why the six-month criterion for HNW?

This is a Medicare regulation for hospice programs. To assure the hospice benefit is used appropriately, a physician is required to certify that an individual will likely die within six months if the disease follows its natural course. There is no time limit on the Medicare hospice benefit, provided criteria continue to be met.

Frequently Asked Questions about Lopez Island Hospice, & Home Support, Hospice of the Northwest, and Palliative Care Services, con't.

How are the different hospice and home support services paid for?

There is no charge for any service provided by LIHHS. LIHHS is a non-profit organization supported by donations, with services provided by volunteers. All HNW services, including medical care and medications related to the terminal illness, are covered by Medicare, Medicaid and most private insurers.

Are there times LIHHS and HNW work together?

Yes. When a Lopez resident is receiving end-of-life services from HNW, many in-home services may also be provided by LIHHS volunteers; we make every effort to coordinate resources, referrals, and recommendations. Spiritual and bereavement support teams are made available from either or both organizations, according to the wishes of the patient and family.

What is palliative care? What are the differences between palliative and hospice care?

Palliative care is whole-person care that strives to relieve the symptoms and stresses of a disease or disorder, whether or not it can be cured. A person can have palliative care at the same time as treatment focused on cure. Palliative care is provided by an interdisciplinary team, usually working together in a hospital setting. Hospice is a specific type of palliative care for people who are nearing the end of life and are not seeking curative treatments.

Does medical hospice or palliative care depend on sedation to manage pain?

Most people fear pain more than death or the dying process, yet they may also fear that nurses will intentionally sedate them to manage pain. The individual patient's wishes are assessed, as well as the level of pain and appropriate medications, starting at low dosages. In addition to physical pain, hospice helps patients and loved ones manage the emotional, psychological, and spiritual struggles that may surround the end of life. Hospice care is not about giving up hope; hospice is about maintaining hope as it is continually redefined, and it is about making the last stages of life as comfortable, painless, and meaningful as possible.

What does LIHHS provide other than home support services?

LIHHS serves Lopez Island in many ways, including no-cost loans of durable medical equipment, group and individual support for caregivers, the bereaved, and for people living with cancer. LIHHS also offers community education programs and volunteer education.

What if I have further questions about these services or organizations?

Call Lopez Island Hospice & Home Support at 468-4446, Mon-Thurs 10am-12noon or 1-3pm. Our website also has many resources; lihhs.org

Call Hospice of the Northwest at (800) 894-5877 or (360) 814-5550, or visit hospicenw.org

Palliative care teams currently serve inpatients at Skaget Valley Hospital in Mt. Vernon, PeaceHealth St. Joseph in Bellingham, and at all major hospitals in Seattle.