

An aerial photograph of a multi-lane highway bridge crossing a wide, blue river. The bridge is flanked by green trees and grass. In the background, there are large, forested mountains under a clear blue sky. The text 'PALLIATIVE CARE ROAD MAP' is overlaid on the left side of the image.

PALLIATIVE CARE ROAD MAP

A GUIDE for living with serious illness and conditions
for patients and those who care for them



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PALLIATIVE CARE ROAD MAP

QUESTIONS YOU MAY HAVE ALONG THE WAY

When healthy: At any age

- Why do I need to think about this when I am healthy?
- What would I want if I become seriously ill or injured?
- What is the difference between a living will and an advance directive?

Worried about symptoms

- When should I see a healthcare provider and what questions do I need to ask?
- Where can I get more information about my specific symptom and treatment options?
- What do I need to consider if I become seriously ill?

Diagnosis

- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

Early in the journey

- What can I expect now?
- How do I set priorities?
- How will I manage my daily life, including employment, family, etc., now and in the future?

Changes: When the illness or health condition worsens

- What will happen to me in the future?
- Who will provide the help I might need?
- Is my healthcare agent prepared to follow my wishes if I become unable to speak for myself?

Recovery and survivorship

- How do I live with the threat of my illness or condition coming back and what will happen if it does return?
- How do I live with the after-effects of treatment and the trauma I've experienced?
- Will the old me ever be back?

End of life, dying, and death

- How will I know I am nearing the end of my life?
- What are my ideas about a good death?
- How can I make sure my wishes about the end of my life are expressed and followed?



WELCOME

We are pleased to offer you the **Palliative Care Road Map: A guide for living with serious illness and conditions for patients and those who care for them.**

We hope this road map helps people who have a serious illness or health condition, and the people they love, to find a way through the experience with less confusion and more awareness of the supports available. Serious conditions often cause difficult symptoms, challenging treatments, and caregiver stress. Fragmented care and frequent transitions between care settings, unmet needs, and increased responsibilities put stress and burden on patients, family members, and other caregivers.

This road map seeks to lessen the burden by helping people make the experience a bit more predictable and manageable. The road map will help you understand palliative care and what it can offer.

The use of the term “family” throughout this document means anyone that you consider close to you; they may or may not be blood relatives.

Key terms can be found on page 28. On page 32 you will find a list of **Resources**.

What is palliative care?

Palliative care is specialized care for people living with serious illness and health conditions. Care focuses on relief from the symptoms and stress of the illness and treatment – whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones, and other care companions. It is appropriate at any age and at any stage in a serious illness or health condition, and can be provided along with treatment focused on curing. Palliative care facilitates patient goals, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care. Most palliative care services are an additional support that does not disrupt your relationship with a primary care provider or other specialists.

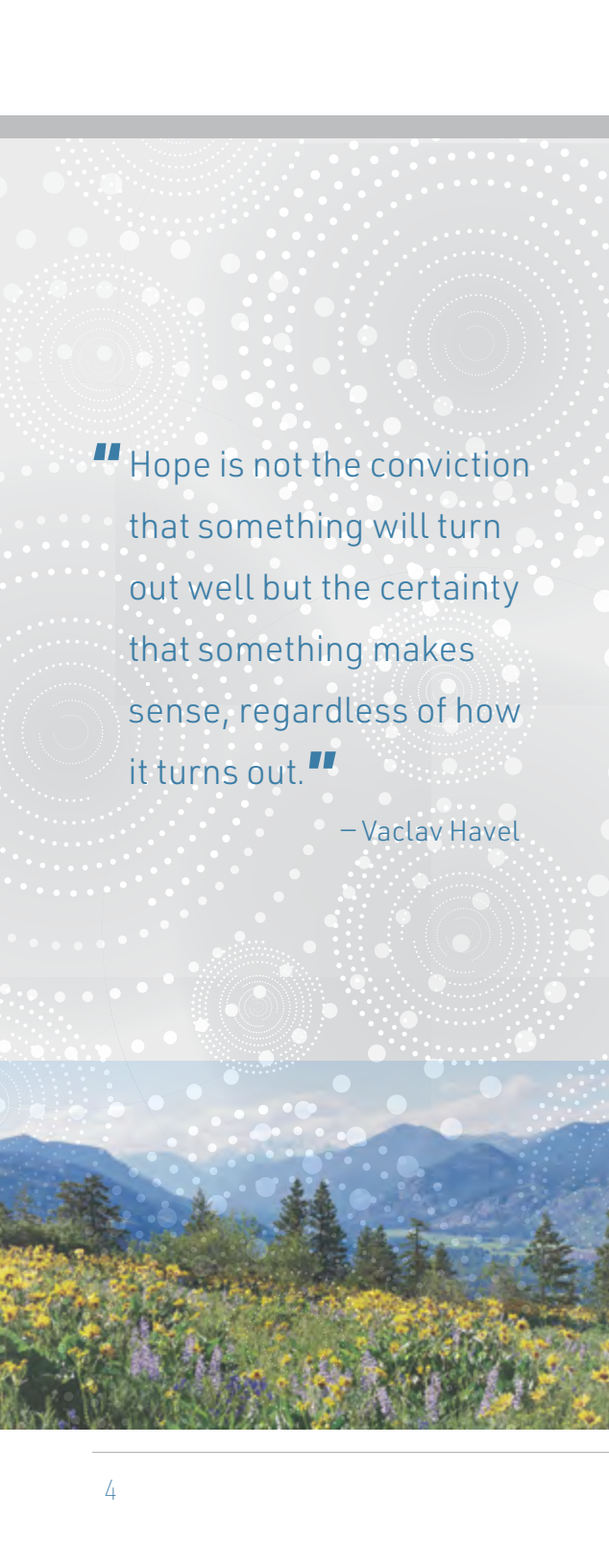
“When we are no longer able to change a situation, we are challenged to change ourselves.”

– Viktor Frankl

Palliative Care-Enhanced Model



Adapted from Pippa Hawley, Bmed, FRPC, University of British Columbia, Head of Palliative Care Division



“ Hope is not the conviction that something will turn out well but the certainty that something makes sense, regardless of how it turns out. ”

– Vaclav Havel

WHAT DOES HOPE MEAN?

When you consider hope, you might think of hope as a wish that everything will turn out well.

When you receive the news that you have a serious illness or health condition, you may hope that eventually you will be able to return to the life you were living before the illness or injury. However, that may not be possible.

Hope can be a way of admitting you cannot predict how things will turn out and staying curious. Hope may be a way of merely staying open to the unexpected and recognizing the limits of your influence.

Hope can be about small things, like the hope that you may have enough energy to do an activity you enjoy. Hope is about things you want to happen.

There is a myth that acknowledging there may be no cure for your illness is considered giving up, and losing hope. Life is not all or nothing. Accepting the serious nature of your illness can co-exist with hope. Your hopes may change with time as your illness or condition progresses and circumstances change. We always can find hope. Hope is not necessarily the same as optimism. Hope can be viewed as an openness to possibility.

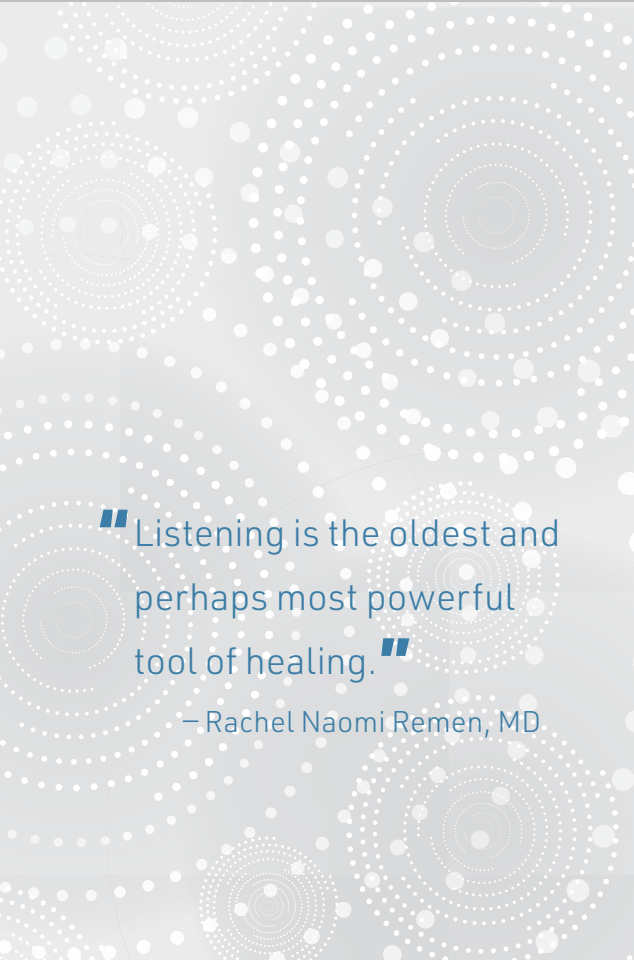
Examples of hopes while living with a serious illness or health condition:

- Hope for honest conversations with those you love.
- Hope for relief from suffering.
- Hope for the courage to walk forward.
- Hope to find meaning in each day.
- Hope to love others wholeheartedly.
- Hope that no matter what happens, you will find a way through.
- Hope to live with purpose and meaning.
- Hope for the wisdom to know when to stop certain things and begin others.

“More than a mere belief,
hope is a conviction.
It’s the knowledge that
we can and will overcome
challenges...”

– Tanya J. Peterson





“Listening is the oldest and perhaps most powerful tool of healing.”

– Rachel Naomi Remen, MD

CULTURE AND SPIRITUAL PRACTICES

Recognizing differences in the way we travel the road

Experiencing a serious illness or a long-term condition is deeply personal. Your values and experiences come to the surface when you seek care and may be shaped by your family values, cultural or ethnic identity, and/or religious or spiritual beliefs.

If you are part of a faith-based, religious, or cultural minority group, you may find it challenging to find providers who demonstrate that they understand your values and preferences. Sometimes your beliefs and expectations about care may collide with your healthcare professional's beliefs and expectations about the way things should be done.

Additionally, the quality of our palliative care journey is also determined in part by our access to social and economic opportunities; resources and supports available in our homes, neighborhoods, and communities; the quality of our schooling; the safety of our workplaces; the cleanliness of our water, food, and air; and the nature of our social interactions and relationships.

You can ensure that your unique needs are addressed by considering the following questions:

- **Who is important to include in decision making and how much information do you as the patient want?**
 - Do you come from a culture where each individual person makes their own choices? Or does your cultural practice consist of listening to multiple members of your family or group? Or does an elder member of the family guide most decisions?
 - How much information do you want your provider to give you about your diagnosis? In some cultures, the family filters the medical details that are provided to the patient.
- **Do you trust your healthcare provider to make good decisions for you?**

Historically, some groups have been denied access to care, or given lower quality care based on their identity. A lack of trust in the system may impact the way you interact with your healthcare providers.

- **Is your own native language different from your healthcare providers?**

If so, you have the right to request interpretive services so that you can better understand your diagnosis and treatment options. Family interpreters may seem like they would be perfect for this task because they also can be comforting; however, having a friend or family member as an interpreter is rarely the best thing to do.

- Friends and family members have personal and emotional attachments. They may not want to confuse or upset you or be the bearers of bad news, so they may withhold crucial information.
- Friends and family members may not be fluent in all the legal, medical or technical terminology they are trying to interpret. They may omit key words, resulting in an inaccurate interpretation.

Sometimes this puts the responsibility on you to share your beliefs, concerns, and needs with providers. Here are some questions you may want to use to guide discussions with providers:

- **You may want to know everything about your medical condition or you may prefer a family member to receive the information instead. Do you have a preference?** If so, make this preference clear to your provider and let them know who should be given the information.
- **Do you usually make your own medical decisions, or does someone help you with that?** Is there someone you would like to bring with you to help you talk with your provider? Make sure your provider knows how you would like decisions made and it is often helpful to bring someone with you.
- **Is there anything you want your provider to know about you (family, faith, community, or beliefs) that might be helpful in designing your care?** Sometimes people are uncomfortable with discussions about issues related to serious illness care with someone from a different race or background. Do you have any feelings about that which would be helpful for your provider to know?

Questions adapted from [Cultural Diversity, Spirituality, and End-of-Life Care](#), James W. Green.



“Healing’s opposite is judgment.”

– Hugh Prather

“In a healthcare system focused on fixing things, having something that cannot be cured can make you feel like you are not in sync with the care team. The palliative care team understands.”

– Patient

HEALTHCARE CONVERSATIONS

Making the most of your appointments

- Do not assume your healthcare provider knows what you do or do not understand. You can help by offering your own sense of that, for example:
“I understand the symptoms I am likely to face as this progresses and partially understand when I should call, but feel like I really do not have a grasp of my treatment choices.”
- Ask for clear guidance on what is a life-threatening condition for you based on your diagnosis. Make a plan for when you should call the clinic, when you might need to see each particular specialist, and when to seek emergency care.
- You have the right to understand the risks and benefits of a treatment as well as the risks and benefits of NOT having a particular treatment. Be sure you understand all four possibilities: risks of treatment, benefits of treatment, risks of no treatment, and benefits of no treatment.
- You also have the right to explore alternative and complementary approaches.
- Make sure your advance care plan documents are filed with your provider(s) and you have discussed this plan with your primary provider.

Communication Tips

- Before the appointment, gather questions as you think of them.
- Prioritize your questions, there may not be time to make it through all of them in a single appointment. Ask for a longer appointment if you have a lot of concerns or have to travel a long way.
- If possible, take along someone you trust to help you ask your questions, understand the information provided, take notes, and debrief with you afterwards.
- Try to anticipate the best time of day for you and try to schedule appointments for times when you have the least difficulty with symptoms.
- Remember this is your care, and your concerns and values should guide decision-making.

Where can you receive palliative care services?

Palliative care services begin primarily in the hospital setting as a consultation and can also begin as an outpatient. You can request palliative care services at any point in a serious illness or condition. Hospice and home health agencies may offer palliative care services as well as primary care clinics, oncology clinics, emergency departments, and other community-based organizations, such as a coalition of rural health organizations working as a team. Rural communities are increasing the number and access to programs and services, as well as innovations such as telemedicine.

Who is on a palliative care team?

A typical team has a physician, physician assistant or advanced registered nurse practitioner, registered nurses, pharmacist, social worker, and chaplain. The team members work in close coordination so that each member of the team understands what the goals of care are for the patient and is aware of how the team will contribute to help meet those goals.

For concerned family members, friends, and caregivers

Sample questions and phrases for a conversation about serious illness and health conditions:

- What do you understand about your illness?
- What have you taken away from what your healthcare team has said so far?
- I can see this news is not what you were hoping for.
- I wish you had received better news.
- I can only imagine how this information feels to you.
- I appreciate that you want to know what to expect.
- Given this situation, what's most important for you?
- Going forward from here, what are you hoping for?
- You are about to tell them something important – you can give a warning such as: “We need to sit down and talk, things are quite serious.”

GETTING YOUR AFFAIRS IN ORDER

ADVANCE CARE PLANNING

Making healthcare decisions

for yourself or someone who is no longer able to do so can be overwhelming. That's why it's important to get a clear idea about preferences and arrangements while you can make decisions and participate in legal and financial planning together.

Use this checklist to ensure

healthcare and financial arrangements are in place before serious illness or a healthcare crisis. Identify a family member, close friend, or community organization that can assist with the creation of these documents.

- ✓ **Start discussions early** with your loved ones while everyone can still help make decisions.



- ✓ **Create documents** that communicate **healthcare, financial management,** and **end of life** wishes for yourself and the people you care for, with legal advice as needed.



- ✓ **Review plans regularly,** and update documents as circumstances change.



- ✓ **Put important papers in one place.** Make sure a trusted family member or friend knows the location and any instructions.



- ✓ **Make copies** of **healthcare directives** to be placed in all medical files, including information on every doctor seen.



- ✓ **Give permission** in advance for a doctor or lawyer to talk directly with a caregiver as needed.



- ✓ **Reduce anxiety** about funeral and burial arrangements by planning ahead.



WHAT HAPPENS IF I DON'T CHOOSE A HEALTHCARE AGENT?

WASHINGTON STATE LAW LISTS WHO WILL MAKE HEALTHCARE DECISIONS FOR YOU IF YOU CANNOT

Healthcare decisions hierarchy

If you don't choose someone to make decisions for you and you can no longer speak for yourself, then Washington state law sets the order for those who will make decisions about your healthcare (your healthcare agent).

More than one person in a group

If any group (like adult children) has more than one person, all the people in the group must agree to the same care. If the group can't agree, then a guardianship may have to be filed to get a decision on the healthcare you need.

State-Appointed Guardian (This is rare and occurs if no one listed below is available to help make medical decisions.)



Healthcare Agent appointed in a written and signed Durable Power of Attorney for Healthcare



Spouse or Registered Domestic Partner (even if separated)



Adult Children



Parents



Adult Siblings



Adult Grandchildren



Adult Nieces and Nephews



Adult Aunts and Uncles



Close Friends (who meet certain limited criteria)





🎯 WHEN HEALTHY: AT ANY AGE

You may be wondering

- Why do I need to think about this when I am healthy?
- What would I want if I become seriously ill or injured?
- What is the difference between a living will and an advance directive?

What to expect

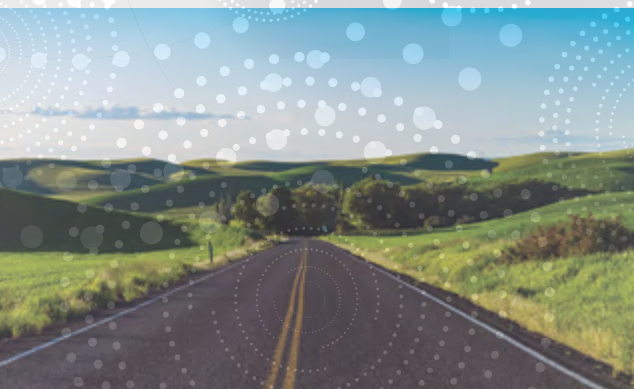
- It may seem odd to plan for a serious illness or health condition when you are healthy, but illness or injury can happen at any time.
- The people who love you will be less distressed if they know what you truly want, so they can support your wishes if you are unexpectedly unable to speak for yourself.
- Some people engage in this kind of discussion with ease, others have discomfort and wish to avoid it.

What you can do

- Reflect on what is most important to you. You might want to consider this question “What ability can I not live without?” and “What am I willing to go through for the chance of more time?” The answers will guide what you write in your advance care plans.
- Ask your family to participate in advance care planning conversations and talk regularly. Advance care planning is not a “one and done” kind of conversation and may need to be revisited, particularly as life circumstances change.
- Ensure that your other legal and financial plans align with your values.
- Plan for and pay in advance for the disposition of your body; cremation, burial, or some of the newer alternatives such as green burial.

“This very moment is the perfect teacher, and lucky for us, it’s with us wherever we are.”

– Pema Chödrön



LEGAL TIPS AND RESOURCES

As a patient, it is important to know your rights. You have the right to make decisions based on your own value system and beliefs.

- You can be given treatments only with your informed consent. That means you understand the risks as well as the benefits of having or not having treatment.
 - You have the right to be given full information in order to make decisions.
 - You have the right to decide what treatments you do or do not wish to have.

But what happens when you are no longer able to make your own medical and financial decisions? Who would you trust to make these decisions?

Talking with your loved ones and healthcare providers is a valuable way to make sure your voice is at the center of your own care. After talking, write down your choices and share them with family, close friends, and healthcare providers. The best way to make sure your wishes are followed is to write your wishes down in an advance directive legally executed under Washington state law and appoint a trusted person to be your healthcare agent in a medical durable power of attorney.

Resources

Northwest Justice Project (NJP) is Washington's largest publicly funded legal aid program. NJP partners with healthcare providers across the state to address the social determinants of health. NJP has a number of self-help resources available on Washington Law Help including topics such as health and seniors. <https://www.washingtonlawhelp.org/issues/aging-elder-law/powers-of-attorney-health-care-directives>
<https://www.washingtonlawhelp.org/issues/aging-elder-law/health-care-for-seniors>

Washington Elder Law Academy Lawyer Referral can refer you to an Elder Law Attorney who are especially aware of and concerned with the special issues pertaining to the practice of elder law in Washington state. Attorneys can assist with estate planning, planning for incapacity with durable powers of attorney for financial and healthcare decisions, Medicaid qualification and asset protection matters, guardianships, and probates. <https://waela.org/>

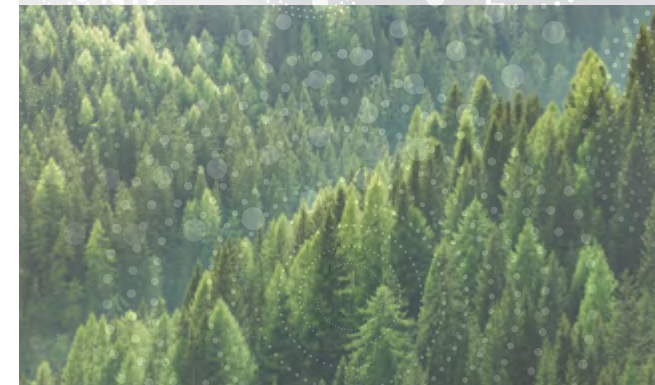
Don't procrastinate.
It always seems too early until it is too late.

Choose someone to speak for you who will implement your point of view.

None of us can ever know when it might be our time to go.

Talk about what matters to you with someone who will carry through.

– Excerpted from "I've Got Mine"
Lyrics and music by Marie Eaton
©2019





WORRIED ABOUT SYMPTOMS

You may be wondering

- When should I see a healthcare provider and what questions do I need to ask?
- Where can I get more information about my specific symptom and treatment options?
- What do I need to consider if I become seriously ill?

What to expect

- Understanding your symptoms can be stressful. A medical evaluation can be the best way to sort out “Is this my imagination or is something really going on?”
- Determining the reasons for symptoms is not always simple. Medical assessments may be a frustrating and involved process with steps forward, backwards, and sideways.
- Waiting between your medical tests and receiving results is often the most stressful time and it’s normal to feel anxious.

What you can do

- Schedule a medical appointment with your primary care provider (doctor, physician assistant, or nurse practitioner) to assess your symptoms. Write down your current symptoms before the appointment, so you can remember everything you want to address. Take notes at the appointment. Taking a family member or friend can be helpful to offer a “second set of ears.”
- Discuss concerns with family, other trusted people, or supportive professionals.
- Try not to self-diagnose. Keep sorting out facts from worries and remind yourself that while it is natural to imagine many possible outcomes, it is healthy to focus on what is actually known.
- Get information from reliable sources. See the sidebar on page 15 to help you determine if a source is trustworthy.

“What’s important to understand is that those in healthcare may tend to forget how complex this is for the uninitiated.”

– Family member

To help support a person living with worries about a serious illness or health condition

- You may need to gently encourage a healthcare appointment if the person has symptoms but seems reluctant to learn about a possible diagnosis.
- Offer to go along to a healthcare appointment and take notes.
- Offer empathy and listen. Sometimes it is best to withhold advice.
- Offer practical support such as rides to appointments.

How a person worried about a serious illness or health condition can support family members

- Be direct about your needs and don't expect others to read your mind.
- Organize your legal and financial paperwork. Make your financial resources explicitly known to those who need to know.
- Execute your advance care directive and appoint the person who you want to be your healthcare agent. This needs to be someone you trust to follow your wishes, rather than imposing their own.
- Remember your family members will have their own fears and sorrow and may need support from others.
- Guide family members to reliable sources of information

How to identify reliable information on the Internet

- **Author** – Information on the internet with a listed author makes it more likely the author is willing to stand behind the information presented.
- **Date** – By including a date, the website allows readers to make decisions about whether that information is recent enough for their purposes.
- **Sources** – Credible websites should cite the source of the information presented.
- **Domain** – The domain .edu is reserved for colleges and universities, while .gov is a government website. These two are usually dependable sources (occasionally a university will assign an.edu address to each of its students for personal use, in which case use caution.) Be careful with all other domains as the author may be trying to persuade or offer information that is not trustworthy.
- **Site Design** – A well-designed site can be an indication of more reliable information. Good design helps make information more easily accessible.
- **Writing Style** – Poor spelling and grammar are an indication that the site may not be trustworthy.

Adapted from the University of Wisconsin



DIAGNOSIS

You may be wondering

- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

What to expect

- You may not fully understand what your condition means. You might feel embarrassed about things that are confusing and be reluctant to ask questions.
- You are likely to experience many different emotions.
- You may wonder about the future, what will happen next, how the illness will progress, and what will be in your control to influence.
- You may realize your needs are no longer met by a member of your present healthcare team. It can be hard to make a change in your care team, but can make a large difference in trust and well-being.

What you can do

- Gather information and ask questions. You may want a second opinion.
- You can decide how much privacy is important to you and who will have access to what information. Decide who needs to be with you to hear news and help make significant decisions. Consider which family and friends can be “real” with you and offer a sense of ease.
- Know you don’t have to do it alone. Put together a team and a list of specific actions where you will allow others to help you, for example rides to appointments, walking a dog, researching resources, or picking up prescriptions.
- You have the right to understand the risks and benefits of treatment including non-traditional or complementary approaches. You also have the right to understand the risks and benefits of not choosing a particular treatment.

“Life is choices and they are relentless.”

– Atul Gwande

- Ask your healthcare provider about palliative care and how it can help you and your family.
- Review your health plan benefits, including palliative care coverage. In Washington state, you can make changes based on a change in health even if it is not open enrollment. Review any Long-Term Care Insurance policies. Sometimes there is a waiting period to begin services.
- Check to see if there are Veteran's Affairs benefits available, this can often take time to get set up if you are not already in the system.
- Begin or complete legal and financial planning. Seek any needed financial counseling. Review documents you already have in place to ensure your current wishes are reflected.

To help support a person diagnosed with a serious illness or health condition

- Ask what they want and need. Recognize that the person's needs and desires may change. Offer specific helpful actions as able.
- Depending on the level of illness, set up delivered meals or arrange for people to mail cards.
- Support a conversation about who to tell about the diagnosis, how to tell, and the circumstances where privacy takes priority over telling.

How a person with a serious illness or health condition can support family members

- Recognize that some illnesses, such as dementia and Parkinson's, changes your ability to have conversations, so express your needs while you still can.
- Create a notebook to help your family find important documents, cards, numbers, and Personal Identification Numbers (PINs), such as social security, health plan, and driver's license.
- If you have young children at home, seek support and learn how to discuss the situation with them honestly, but at a developmental level that fits.

“Every part of our life was affected, from food to finances.”

– Patient



“...let’s face it , it’s so inspiring and such a relief when you can organize things so that a small miracle appears to have taken place and that love once again turned to be bigger than fear and death and blindness.”

– Anne Lamott

EARLY IN THE JOURNEY

You may be wondering

- What can I expect now?
- How do I set priorities?
- How will I manage my daily life, including employment, family, etc., now and in the future?

What to expect

- Symptoms may start to impact your daily life and may come and go unpredictably.
- You may be weighing possible treatment options, each with their own set of risks and benefits. You may find this challenging.
- You may have spiritual questions or feel punished or abandoned and say, “why me?”
- Your family and friends may not know what to say and have their own emotions. Some may hover protectively and others might withdraw.
- You may be grappling with the reality that this illness could lead to death in a shorter timeframe than you had imagined.

What you can do

- Revisit what quality of life means to you; your ideas are likely to continue to change as your condition changes.
- Consider an online community, or seeking individual or family counseling to deal with the stress of living with illness and to help clarify what is most important to you.
- Ask your healthcare team what to expect as your disease or condition progresses and how much care or support you might need. Learn about home care services or places that can help if you need more care.
- Take stock of your “new normal” and identify what remains as well as what is lost.



To help support a person living with a serious illness or health condition

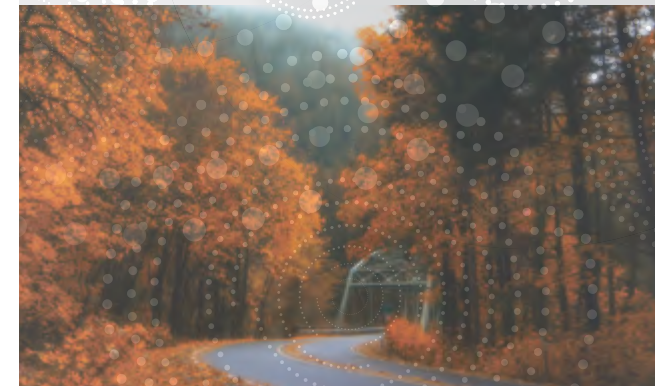
- Ask open ended questions to initiate conversations, and listen.
- Work to find life balance. Try to not give the illness your total focus, and pay attention to cues that your family member may want to focus on other things.
- If you have an idea about how to help, offer your suggestion and ask if it might be helpful. Give the family member room to decline.
- Learn how the person who is ill will be impacted as the condition worsens and consider developing a staged plan for support services.

How a person with a serious illness or health condition can support family members

- Tell loved ones how you are doing and what you need.
- Get information about services to support your family.
- Accept help that others offer and be honest about what is most helpful.
- Show interest in other people and topics outside illness; it is healthier for you and makes life less stressful for others.
- Ensure arrangements and wishes for your care are in place if the illness progresses.
- If you have dementia, Parkinson's, or another condition that impacts thinking and have not yet talked about palliative care or your needs and preferences, talk about it now.

“She knew from the start what she wanted...and what she didn't want. We are so grateful that she talked to us about it.”

– Family member



“...it speaks of such integrity to refuse to pretend that you’re doing well just to help other people deal with the fact that sometimes we face impossible loss.”

– Anne Lamott

LOSS AND GRIEF

Grief comes in many ways as you face a series of losses, particularly as your serious illness or condition progresses. You may grieve feeling good, your health, things you used to be able to do, and other aspects of living impacted by a serious illness.

- Grief does not follow a schedule. There is no time limit on grief and we all grieve in our own ways and at our own pace.
- Sometimes others may mistakenly expect you to be “finished” or to “get over it.”
- Grief does not progress through a sequence of stages. Although a physician and writer named Elizabeth Kubler Ross suggested that grief has elements of denial, bargaining, sadness, anger, and acceptance, she never meant to imply that this is a tidy sequence of stages.
- You may experience “anticipatory grief” as you begin to observe changes and “anticipate” how your illness will interfere with your family, working, or participation in other aspects of life before they are actually impacted.
- Some people might think that anticipatory grief may lessen the pain when the actual loss occurs, but often this is not the case. We may enter a different quality of grief when the loss is final.

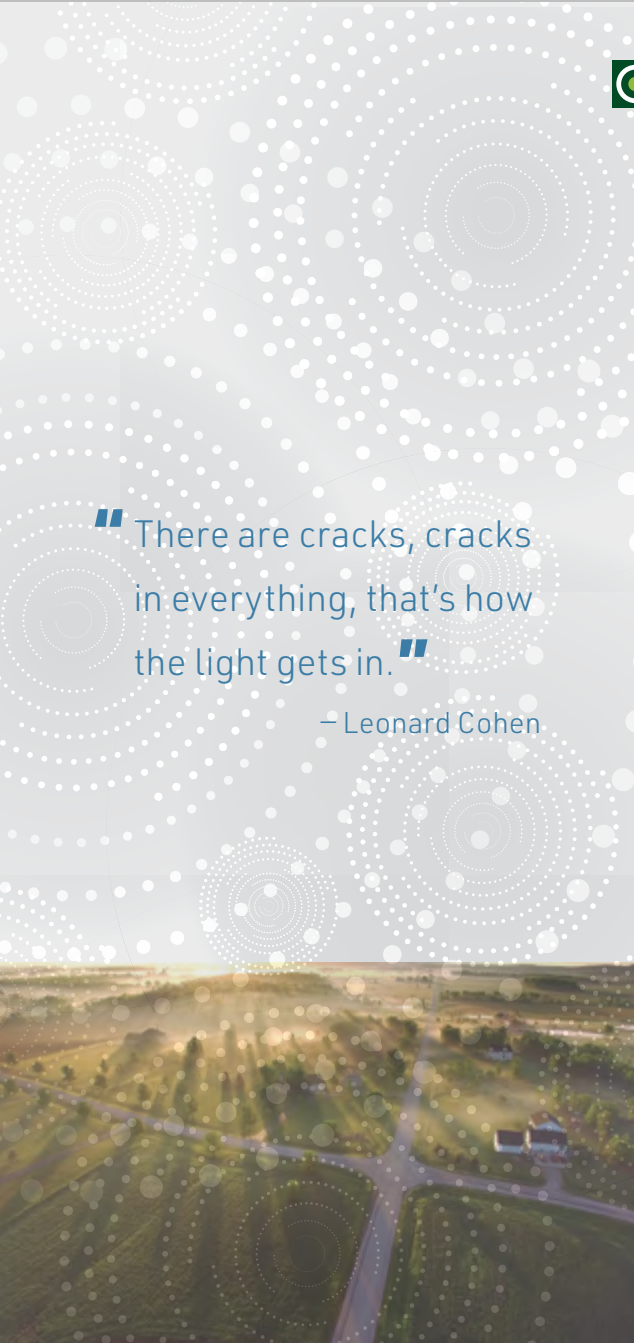
- Your family may also be grieving the loss of your participation in activities or tasks.
- People who are grieving usually find solace in good listeners who know how to “be with” and accept the intensity of the grief without becoming anxious or distant, or taking over the conversation with answers, advice, or their own issues.
- Tell your stories. Grief often involves looking back and sorting through the past.
- Although accepting help from others may feel difficult, grief is a time when we need others more than usual.
- You may find it helpful to talk to others with a common experience, individually or in a support group, so that you have mutual support. Or, you may prefer to be more on your own.
- Some find their grief opens their hearts. You may love and appreciate more deeply.
- Grief is not the same as depression, but can feel similar. The line between healthy grieving and a clinical depression can be subtle and is best assessed by a counselor or healthcare provider.

There is not a cure for grief, but there can be solace when we are with others and understood, realizing we are not alone.

“...mourning is a romance in reverse, and if you love, you grieve and there are no exceptions.”

– Thomas Lynch





“There are cracks, cracks in everything, that’s how the light gets in.”

– Leonard Cohen



CHANGES

When the illness or health condition worsens

You may be wondering

- What will happen to me in the future?
- Who will provide the help I might need?
- Is my healthcare agent prepared to follow my wishes if I become unable to speak for myself?

What to expect

- More symptoms may occur, possibly more often or with greater intensity. New symptoms or complications may arise unexpectedly.
- Illness is unpredictable. You may fear not being able to do the things you enjoy, impact on work, physical changes, loss of independence, and many other things.
- You may find it harder to keep doing all the things you normally do. Fatigue is a large part of many illnesses and can be frustrating. This is sometimes called adjusting to a “new normal.”
- If you experience suffering, you may think you must stick it out or mistakenly think asking for help is a sign of weakness. It takes courage to ask for assistance.
- You may want to re-examine treatment options.
- You may be filled with a deeper appreciation for those you love and for life itself.

What you can do

- Discuss what to expect as your disease or condition progresses with healthcare providers. You have the right to understand the risk and benefits of treatments and to say no to treatments you do not want.
- You may find it hard to know when to accept medications for pain and when to try other options for relief. A palliative care team can offer guidance about pain and control of other symptoms.

- If you haven't already engaged with palliative care, it's not too late. You can receive palliative care without giving up curative treatments. Ask your provider to make a referral.
- Ensure any involved healthcare providers are aware of and will honor your wishes, including those who may support in-home care.
- Assess whether you have taken all the legal steps necessary to have your wishes honored, protect what you have, and look after any dependents.
- A healthcare professional called an occupational therapist can recommend medical equipment or supplies that may help you live more comfortably at home.
- Learn more about hospice. People often express a wish they had involved hospice sooner.

To help support a person living with a serious illness or health condition

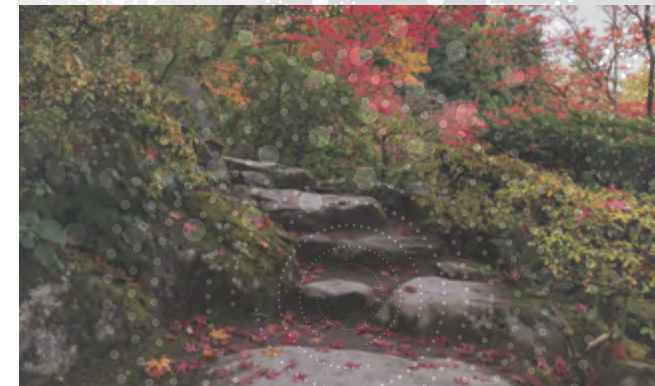
- Encourage conversation about hopes and fears and allow for silence/space.
- Consider respite care to give regular caregivers a chance to take a break and attend to other needs.
- Identify how you will know you need a break or need more help (such as a paid caregiver).
- Help record questions for the healthcare team.

How a person with a serious illness or health condition can support family members

- Help sort out what is the "right" amount of help without intruding on your privacy or independence. Discuss how you can signal family members that are under-helping or over-helping.
- Tell loved ones how you are doing and what you need.

“It's all about the joy of living, and regaining that while you can, even in tiny snippets.”

– Patient





RECOVERY AND SURVIVORSHIP

You may be wondering

- How do I live with the threat of my illness or condition coming back and what will happen if it does return?
- How do I live with the after-effects of treatment and the trauma I've experienced?
- Will the old me ever be back?

What to expect

- Recognize you may feel an odd sense of loss as you adjust to a life that no longer revolves around being ill.
- Your primary care team may or may not understand the long-term effects of your treatments.
- It is natural to feel cautious about accepting that you are in remission or recovery. Caregivers may watch you very closely for the possible return of symptoms.
- You may wonder why you survived, and perhaps feel guilt, especially if you knew others with a similar illness or condition who died.
- Palliative care may continue, particularly if you are dealing with symptoms from the after-effects of treatment.
- 'Graduating' from hospice does not mean that your hospice benefit goes away; you may receive hospice services again if you again become eligible and need these services.

“Something is opening in me, some new eye.”

– Brian Doyle



What you can do

- Make plans to give structure to each day.
- Participate in counseling.
- Reflect on the lessons from your experience.
- Talk with your providers about what to expect and possible treatments going forward.
- Tell your story.
- Volunteering or finding ways to help others may help you get back to feeling whole again.

To help support a person living with a serious illness or health condition

- Recognize your relationship may shift as illness or a health condition is less dominant.
- Listen.

How a person with a serious illness or health condition can support family members

- Understand that people may continue to worry about your health. Give your family and friends time to adjust to the new reality. Those who see you less frequently may still be thinking of you as very ill.

“ We think that the point is to pass the test or to overcome the problem, but the truth is that things don't really get solved. They come together and they fall apart.”

— Pema Chödrön





END OF LIFE, DYING, AND DEATH

You may be wondering

- How will I know I am nearing the end of my life?
- What are my ideas about a good death?
- How can I make sure my wishes about my end of life care are expressed and followed?

What to expect

- Family members and friends may still have hopes for a “miracle” and be conflicted about the best plan.
- Your choice about when or if to move from pursuing curative care to comfort care (or hospice) may require some in-depth conversations about your current status and goals.
- End-of-life stages happen at different speeds for everyone, so a specific date or time is difficult to predict.

What you can do

- Make sure each healthcare team member understands your goals and preferences and have up-to-date advance care documents on record.
- Understand all your options and determine what is right for you. Communicate that to your family and healthcare agent.
- Be specific and let others know what would be most helpful.
- Request a hospice care evaluation if you are concerned about your prognosis.
- If you don't want to die in your home, ask about other places you may be able to receive end-of-life care.

To help support a person living with a serious illness or health condition at the end of life

- Ask what might be comforting (music or pets or visits from friends).
- Explore how to support friends and family members, including children and youth, in their grief.

“...a broken body is not a broken person.”

— Janine Shepherd

POLST Portable Medical Orders

POLST is not for everyone. [POLST](#) is designed for people who have a serious illness or condition, or who are frail or in poor health, regardless of their age. All adults should complete an advance directive. Talk with your doctor/healthcare provider about whether you should also have a POLST form.

- The POLST form is a medical order that can speak for you if you choose to not have life-saving care by an emergency responder outside of the hospital.
- The POLST allows you to let emergency responders know if you prefer NOT to have resuscitation to restart your heart and/or breathing in your home or other settings out of the hospital.
- You and your doctor (or ARNP or PA) can decide together whether it is time to use the POLST to represent your wishes as clear and specific medical orders. Having a POLST form is optional. You should never feel that you must complete one.
- POLST is a portable medical order, not an advance directive, and not intended to replace that document.

The POLST allows you to choose where you might receive what kind of care.

- Choose “Full Treatments” if you would be willing to go to the Intensive Care Unit (ICU) to have your life prolonged;
- Choose “Selective Treatments” if you are willing to go to the hospital but would not want a ventilator to breathe for you or otherwise have your life sustained on machines;
- Choose “Comfort-Focused Treatments” if you prefer to avoid hospitalization, even if it means you might die at home.

The POLST form is designed to move with you from one location to another.

- Some places may ask you to complete a new form. You may request that they honor your existing POLST form rather than completing a new POLST form.
- A healthcare professional can check that these decisions are still your choices and mark a new date and signature on the backside of the form.

“There is a light to all this darkness.”

– Seinabo Sey



KEY TERMS

Advance care planning

Talking with your loved ones and healthcare providers helps make sure your voice is at the center of your healthcare. Advance care planning is a conversation about your wishes. Once you have thought about your wishes, it is important to write them down in legally recognized documents. This is sometimes called a Living Will or Healthcare Directive. The following planning documents will help you express your healthcare decisions and values if you are not able to say yourself what you would want. These documents should be updated regularly and shared with your healthcare agent, loved ones, doctor, and hospital. At a minimum, you should consider completing both a durable power of attorney for healthcare and a Healthcare Directive. A power of attorney for finances is also a good idea and can be included in a single document with your

Durable Power of Attorney for Healthcare.

Healthcare Directive (Living Will or advance directive) is a legal document that tells your provider and healthcare agent what treatments you would or would not want if you were permanently unconscious or not expected to recover. The advance directive includes directions for how to complete it and make sure it is legally valid.

Durable Power of Attorney for Healthcare (DPOA-HC) is a legal document where you can select a healthcare agent to make healthcare decisions for you if you cannot. A person can make healthcare decisions on your behalf under Washington's Informed Consent law even if not appointed an agent in your DPOA-HC, but that person may not be the person you would want to be making these decisions for you. Your execution of a DPOA-HC guarantees that you have your own choice of healthcare agent and also allows you to choose an alternate if your agent is unavailable.

Durable Power of Attorney for Finances (DPOA-Finances) lets you choose a trusted friend or relative to help you with your finances, including buying and selling property, depositing and withdrawing money from accounts, establishing eligibility for public benefits programs, and paying bills. You can still make your own financial decisions if you are capable. You can change or cancel your power of attorney form at any time. Without the DPOA-Finances, almost all care decisions that involve money or other assets will cease until a guardianship is set up, costing thousands of dollars and resulting in a loss of rights and time.

The **Portable Medical Orders (POLST)** form describes the patient's care directions at end-of-life. It is used as a way of letting emergency care providers called to the home know if you do/ do not want to be resuscitated or have other emergency care provided beyond comfort care. It is intended to go with the patient from one healthcare setting to another and includes the following:

- Patient wishes for resuscitation
- Medical interventions
- Antibiotics
- Artificial feedings

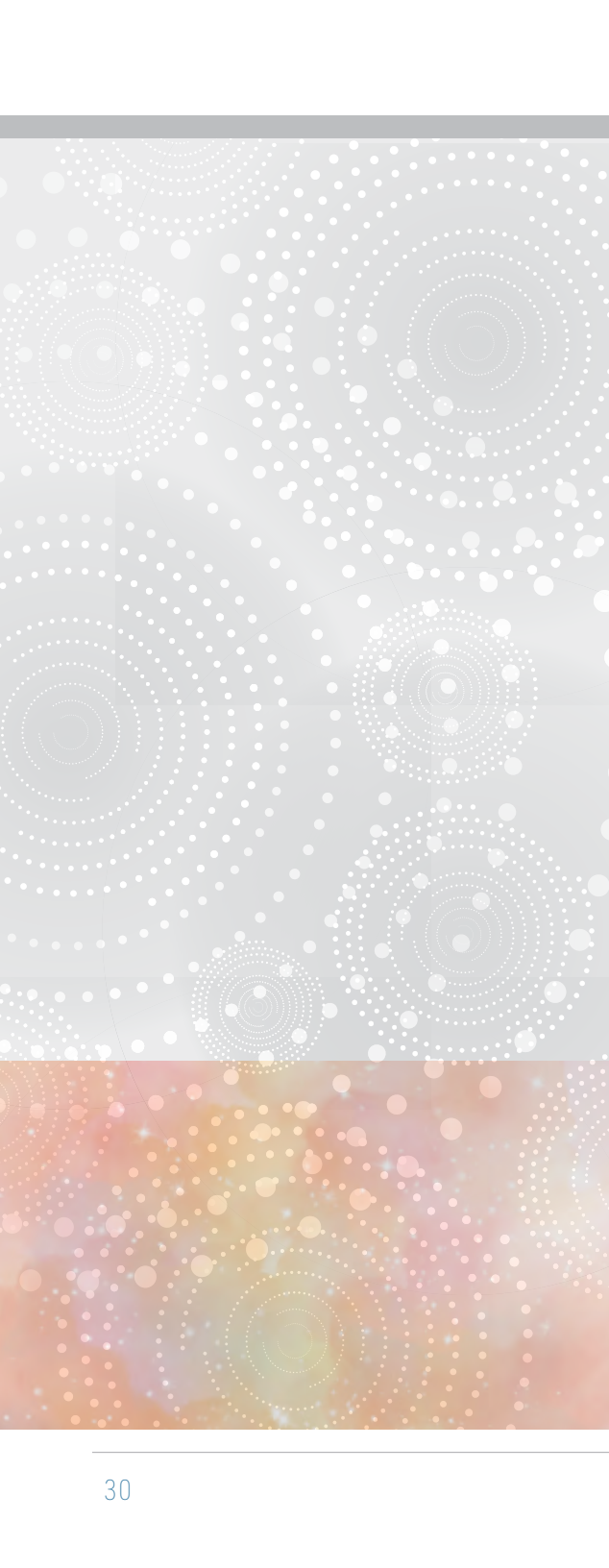
Agency or independent home care?

Agency – Agencies screen, hire, train and supervise staff and then assign a caregiver to you or your family member. If a home care aid is ill or on vacation, the agency will take care of coverage. Though you can express preferences, you have less choice over caregivers. Most agencies will work hard to make a good fit between the home care aid and the client. Agencies generally cost more per hour and you will not have to pay for taxes. Washington state agency caregivers must have a minimum of 75 hours of training. In-Home Care is often paid for privately, through long-term care insurance, veteran benefits or Medicaid. If you are receiving home health services, a home health aide might be a member of the team who assists you.

Independent Home Care Providers – After you do the screening and interviewing, you supervise their work. Like an employer, it is up to you to set expectations and offer guidance if the expectations are not met. This does give you the most say about who provides care. You will likely need a backup because if the main home care aid is gone, you will need a substitute. Most independent contractors charge less than an agency.

All paid caregivers should be trained and credentialed by the state as a Home Care Aide. This assures they have the proper training and credential. Medicaid will pay a portion of the cost of home care and tracks the home care aides serving their clients. Some long term-care insurance policies will pay for home care. Some families chose to pay privately.





Home care agencies employ caregivers to assist with safety, health and independence. Independent home care providers also provide services. Home care is not covered by regular Medicare but may be covered in a few Medicare Advantage plans.

Examples of non-medical services include:

- Activities of daily living, such as assistance with walking, transferring from one location to another, bathing, dressing, eating, toileting, and personal hygiene;
- Homemaking, such as assistance with ordinary housework, essential shopping, meal preparation, and travel to medical services; and
- Respite care, such as assistance and support provided to the family, so family caregivers can have time to take care of their own needs.

Home health is usually ordered by a physician, physician assistant, or advanced registered nurse practitioner at the time of discharge from a hospital or skilled nursing community. You, your family or a nurse may also request physician orders for home health when you have a change in condition. Signed medical orders are needed to start care. Patients often underutilize this benefit that is covered 100% by Medicare or insurance. Once you are referred to home health services, the home health agency will schedule an appointment and come to your home to talk to you about your needs and ask you some questions about your health.

Home health agencies provide skilled nursing, social work and therapy related services to people who are homebound, assisting them to recover and rehabilitate from an illness or recent surgical procedure, or to maintain their highest possible level of health and independence. Some home health agencies provide palliative care services.

A **healthcare agent** is a person you allow to make decisions for you in case you can't make them yourself. A healthcare agent may also be known as:

- An attorney-in-fact
- A healthcare proxy
- A representative
- A surrogate

Hospice provides comprehensive comfort care as well as support for the family, but, in hospice, attempts to cure the person's illness are stopped. Hospice is provided for a person with a terminal illness whose doctor believes he or she has 6 months or less to live if the illness runs its natural course.

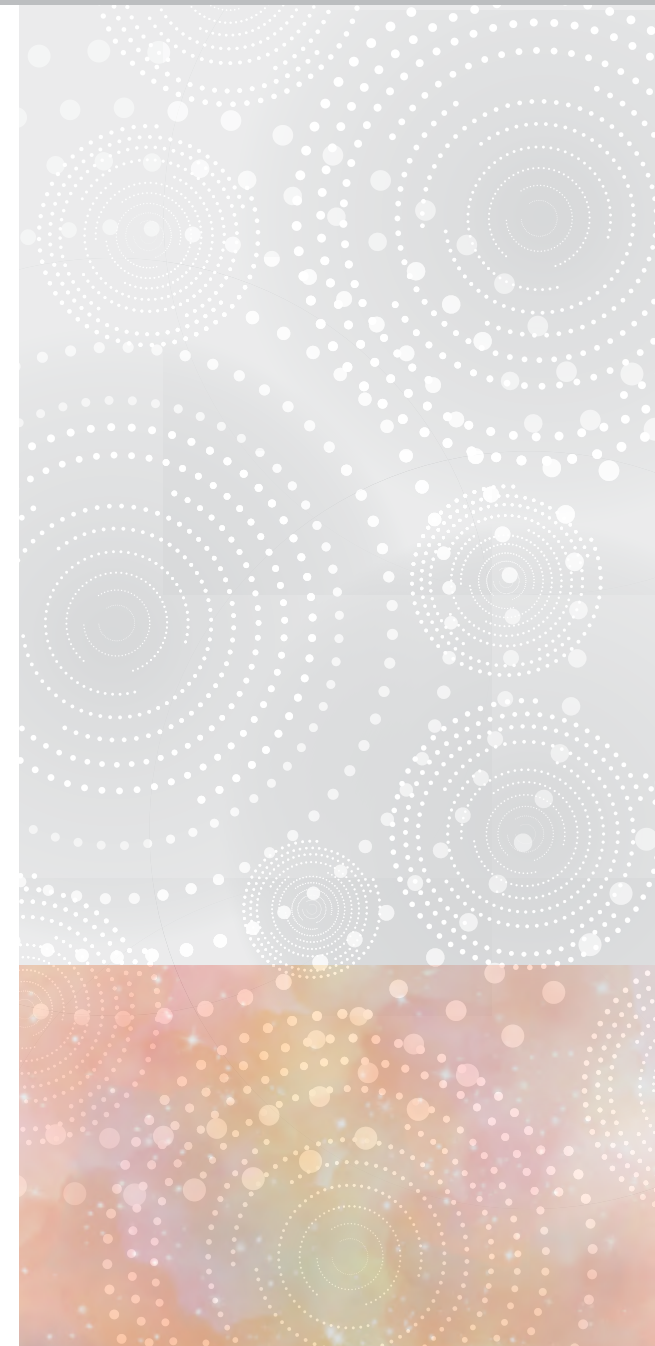
Hospice is an approach to care, so it is not tied to a specific place. Hospice is often offered in the home but also can be provided in nursing homes, adult family homes, assisted living and other supportive residences. There also are a handful of inpatient hospice services in Washington state.

New normal is a term originally used in economics and business and is used to describe what life has become after a large change to circumstances and daily life. It also implies what was abnormal before is now commonplace. The new normal also means you will not be returning to how things were before.

Palliative care specialized care for people living with serious illness and health conditions. Care focuses on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness or health condition, and can be provided along with treatment focused on curing. Palliative care facilitates patient goals, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care. Most palliative care services are an additional support that does not disrupt your relationship with a primary care provider or other specialists.

Serious illness is a condition that “negatively impacts quality of life and daily function, and/ or is burdensome in symptoms, treatments, or caregiver stress... [and] carries a high risk of mortality.” Traditional life-prolonging or curative care often does not meet a person's range of needs as illness progresses.

It is important to note that injuries and other conditions that are not exactly illness may also fit this definition of serious and be appropriate for palliative care. Serious illness may include the worsening of a chronic condition.



RESOURCES

Organizational Websites

The Washington State Hospice & Palliative Organization (WSHPCO) – <http://wshpco.org>

Getpalliativecare.org – <https://getpalliativecare.org/>

The Washington Association of Area Agencies on Aging provides free resources and assistance at local offices – <https://www.agingwashington.org>

Aging Life Care™ links to specialists who act as a guide and advocate for families who are caring for older relatives or disabled adults – <https://www.aginglifecare.org>

The Washington State Health Advocacy Association (WASHAA) – www.WASHAA.org

Washington Home Care Association can assist you in finding a licensed in-home care agency – www.WAHCA.org

Home Care Association of Washington directs you to home health services in your area – <https://hcaw.org>

Carinacare.com matches people who need in-home care with independent contractor home care aids – <https://www.carinacare.com>

The Home Care Referral Registry matches Washington State residents receiving publicly funded in-home care services with screened home care workers – <http://www.hcrr.wa.gov>

End of Life Washington resources and support for terminally ill patients who wish to use the Washington Death with Dignity Act – <https://endoflifewa.org>

Dementia Action Collaborative is a group of public-private partners preparing for the growth of the dementia population in our state – www.dshs.wa.gov/altsa/dementia-action-collaborative

Resources for Legal and Advance Care Planning

Honoring Choices, Pacific Northwest provides information about various end-of-life choices – <https://www.honoringchoicespnw.org/learn/know-your-choices/>

Washington State Medical Association offers information about healthcare directives (living wills) and the durable power of attorney for healthcare – <https://wsma.org/advance-directives>

Washington Law Help has clear and simple forms for durable power of attorney and healthcare directives – <https://www.washingtonlawhelp.org/issues/aging-elder-law/powers-of-attorney-health-care-directives>

Wonderfile provides a central place to store all necessary advance care planning paperwork – <https://endoflifewa.org/choices-and-planning/wonderfile/>

National Hospice and Palliative Care Organization: Guide to Advance Directives has a state-by-state advance directive legally appropriate for Washington – <https://www.nhpco.org/patients-and-caregivers/advance-care-planning>
<http://www.caringinfo.org/files/public/ad/Washington.pdf>

Prepare for Your Care step-by-step program to fill out advance directives – <https://prepareforyourcare.org/welcome>

The Conversation Project includes a getting started guide, a guide for people with Alzheimer's Dementia, and a pediatric version – <https://theconversationproject.org>

Five Wishes provides an advance directive form – <https://www.agingwithdignity.org/five-wishes/individuals-and-families>

The Centers for Disease Prevention and Control extensive annotated guide "Advance Care Planning: Selected Tools for the Public" – <https://www.cdc.gov/aging/pdf/acp-resources-public.pdf>

Dementia Advance Directives

Living with Dementia Mental Health Advance Directive an advance planning document that allows people coping with Alzheimer's disease and dementia to document their wishes about the inevitable challenges related to living with these illnesses –

<https://endoflifewa.org/choices-and-planning/dementia-directives>

Advance Directive for Dementia allows you to indicate how much medical care you would want if you had Alzheimer's disease or another type of dementia – <https://dementia-directive.org>

Tools for Advance Care Planning Conversation

DeathOverDinner.org walks visitors through planning a dinner party designed to engage guests in conversations about death and dying – <https://deathoverdinner.org>

The Go Wish Game stimulates discussions on values and wishes about end-of-life care – <http://www.gowish.org/staticpages/index.php/thegame>

The Death Deck designed with open-ended questions guaranteed to spark discussion around the topic of death – <https://thedeathdeck.com>

'Hello' is a card game that makes the most difficult conversations easier – <https://commonpractice.com/products/hello-game>

Final Roadmap is a toolkit that encourages you to consider your wishes and communicate them to your loved ones – <https://www.finalroadmap.com>

Other Palliative Care Resources

CaringInfo Resources is a collection of resources on topics including how to make decisions, talk to doctor, etc. – <https://www.nhpco.org/patients-and-caregivers/resources>

Meal Train is an organized way for many people to deliver meals over several weeks or longer – <https://www.mealtrain.com/?id=bing&msclkid=c0774b17836b14f3707016each52a522>

Child and Young Adult Resources

Courageous Parents Network provides support for families as they care for a seriously ill child – <https://courageousparentsnetwork.org/>

Soulumination.org celebrates the lives of children and parents facing life-threatening conditions by providing professional photographs of these special individuals and their families, free of charge – www.soulumination.org

Make a Wish grants wishes to children with a critical illness – <https://wish.org>

My Wishes (pediatric) and **Voicing My Choices** (young adults) are advance directives available through Five Wishes focused on younger age groups – <https://fivewishes.org>

Check with your local pediatrician/family practice doctor for hospital or community-based child and young adult palliative care resources.

Child and Young Adult Grief Support Resources


Bridges Center for Grieving Children support for children between the ages of 4 and 18 coping with a loved one's serious diagnosis or death – <https://www.marybridge.org/services/bridges-center-for-grieving-children>

Dougy Center for Grieving Children provides support for children, teens, young adults, and their families grieving a death – www.dougy.org

Safe Crossings Children's Grief Program for children and teens who are facing or have experienced the death of someone significant in their lives – <https://washington.providence.org/services-directory/services/s/safe-crossings-childrens-grief-program>

Seattle Children's Hospital Journey Program provides grief and loss support for any family who has experienced the death of a child – <https://www.seattlechildrens.org/clinics/grief-and-loss>

Not If But When provides book recommendations for young people about death and loss – www.notifbutwhen.org



Camp Erin is a free, weekend, overnight camp for youth who are grieving the death of a significant person in their lives – <https://elunanetwork.org/camps-programs/camp-erin>

Our Treehouse grief group for kids – <https://www.whatcomtalk.com/2019/02/16/our-treehouse-offers-grief-support-in-whatcom-county>

Reach out to your local hospice agency to ask about what is available in your community for grieving children and young adults.

Veteran's Resources

U.S. Department of Veterans Affairs provides palliative care and helps veterans and their families manage illness with plans of care – https://www.va.gov/GERIATRICS/pages/Palliative_Care.asp

CONTRIBUTORS

Anne Anderson
Sue Bergmann
Raleigh Bowden
Becky Brewer
Lisa Brodoff
David Bucher
Stephanie Carpenter
Brenda Charles-Edwards
Kassie Clarke
Kayleigh Creighton
Shawn D'Amelio
Marie Eaton
Leslie Emerick
Sharmon Figenshaw
Donna Goodwin
Jullie Gray
Barbara Hansen
Laura Hofmann
Donna Inglis
Pat Justis
Lynne Korte

Todd Larson
Jessica Martinson
Christine Opiela
Janet Ott
Lynn Reinke
Sarah Rial
Carla S. Ryan
Tatiana Sadak
Richard Scholtz
Janelle Shearer
Lauri St. Ours
Tammy Tarsa
Cynthia Tomik
Gregg VandeKeift
Pat Waber
Christina G Wagar
Deb Watson
Patricia Weber
Vonda Witley
Melody Woodrich-Fernando
Charla Wright

Inspired by the Dementia Action Collaborative of Washington State, developers of the **Dementia Road Map: A Guide for Family and Care Partners**, the board of the Washington State Hospice and Palliative Care Organization (WSHPCO) worked with the Joint Legislative Executive Committee on Aging and Disability co-chaired by Representative Steve Tharinger (24th District) and Senator Barbara Bailey (10th District) to sponsor funding to write and distribute a similar road map for people with serious illness and health conditions, and the people who love them. The Washington State Department of Health was honored to be selected by WSHPCO to lead the **Palliative Care Road Map** work.



Rural Health / Office of Community Health Systems
Health Systems Quality Assurance
Washington State Department of Health
111 Israel Road SE / MS 47853
Tumwater WA 98504-7853

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