



2024 Volunteer Manual


EvergreenHealth
HOSPICE CARE CENTER

Table of Contents

The Volunteer.....

- Who?.....
- What?.....
- When and Where?.....
- How?.....
- Our goals for this training.....
- How To Listen.....
- Compassionate Presence; Listening with The Heart.....
- We Honor Veterans.....

The Patient.....

- Spiritual Issues in The Care of Dying Patients.....
- Family Systems Theory.....
- Pain and Symptoms at End of Life.....
- Pain And Pain Management.....
- Managing Pain.....

Dying.....

- What To Expect As End Of Life Approaches.....
- End-Of-Life Nutrition And Hydration.....
- Signs And Symptoms Of Approaching Death.....
- Understanding the Final Messages of the Dying.....

The Volunteer and the Patient.....

- A practical guide for a respectful visit.....
- Patients, Relationships, And Boundaries.....
- You and your patient or caregiver.....
- Setting Healthy Boundaries.....
- The End Of The Relationship.....

Diversity And Culture In End-Of-Life Care.....

Diversity in the Hospice Setting.....

Grief.....

Myths About Grief.....

Definitions of Loss and Grief.....

Anticipatory Grief.....

Grieving Styles.....

What To Expect From Grief.....

DAILY SURVIVAL KIT FOR SERIOUS ILLNESS AND GRIEF.....

Self-care.....

Caregiver’s Self-Care Manifesto.....

Infection control, Ethics, Policies, & Resources.....

Infection Control.....

Bloodborne Pathogens.....

Tuberculosis.....

When To Stay Home: Work Restriction Policy.....

Ethical Dilemmas in Hospice Care.....

EvergreenHealth Hospice Volunteer Program Procedures and Regulatory Information.....

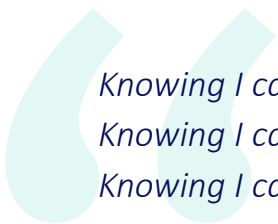
HIPAA: Health Insurance Privacy & Accountability Act.....

Patient Safety.....

Environment of Care.....

Safety Guidelines.....

Policy: Code of Conduct.....



Knowing I can be a respite for the others in the home who need a break.

Knowing I can be a listener to and for the family or others in the home.

Knowing I can be there for the one dying.

Knowing I can be the Reiki Master who can ease the discomfort.

Knowing I can be the one on the other end of the phone listening.

Knowing I can provide words of encouragement.

Knowing I can.

Volunteer Sue McCormick

Welcome! We are so glad you decided to join us!

The Volunteer

WHO? YOU!

Volunteers Are The Heart Of Hospice!

Being a hospice volunteer means many things, of course. Most significantly, it means that you have chosen to share your skills, empathy, and compassion with your community, for which we are endlessly grateful. Thank you! We are acutely aware that every single one of our volunteers has a rich life and could be giving their time and expertise to any number of organizations. We are honored that you chose EvergreenHealth Hospice as the recipient of your generosity.



Hospice volunteering means being a part of our very special community. Your work is valued by our staff and management, and you are considered a member of the patient's care team. Many of our volunteers and clinicians have been working together for years, and the rest of the team truly relies on the insights and practical help they get from volunteers. Our volunteers have also formed a very strong community amongst themselves. For many of them, volunteering at EvergreenHealth Hospice is a wonderful way to meet like-minded people, and to socialize with new (that's you!) and old friends. As a volunteer, you are an ambassador for EvergreenHealth Hospice out in the community AND the patient's ambassador to the rest

of their team. As the only member of the team who shows up for the patient without asking anything of them, you develop a unique relationship with them and their caregivers; volunteers are often privy to information or observations that the rest of the team is not aware of. Your reports are very important thanks to that privileged position.

Volunteer support eases the path of our patients, their families and caregivers, and benefits our clinicians and staff. That support can take the form of being the friendly face who greets those coming to the Hospice Care Center, a sympathetic ear telephoning after a loved one has died, an in-home volunteer who sits quietly with a sleepy patient while the caregiver has a break, a companion who shares their dog with our patients, or an office volunteer who helps to keep things humming along for clinicians and the Volunteer Coordinators. Supportive volunteers can be patient facing, staff facing, both, or neither (there is always work to be found, if you prefer solitary or remote tasks).

In keeping with the hospice philosophy of self-determination, hospice volunteering also means deciding which part of our program suits you best. We never assign our volunteers to positions without their consent, and we do not expect anyone to volunteer in a way that makes them feel anxious or uncomfortable. We have many different roles to fill and are happy to help volunteers find the one that meets their needs. If you are finding your volunteer work challenging in some way, the Volunteer Coordinators are here to help. We are always happy to listen and, if you would like to make a change, we will work with you to figure out what your next best step is. We will do that as many times as it takes for you to find your place.

Every little bit helps. How do you fit in? In whatever way works best for you.

WHAT?

What Is Hospice And How Does It Work?

The modern hospice movement began with the 1967 opening of St. Christopher's Hospice in London. It was established by Dame Cicely Saunders, an English physician who began her career as a nurse to the terminally ill in 1948. During a 1963 visit to Yale University, Dr. Saunders gave a lecture that introduced hospice care to the United States. That talk formed the basis of hospice care as we know it today. In 1982, Congress approved the creation of a Hospice Medicare benefit.

Hospice is a philosophy, not a place. The Latin root of the word is "hospis," which means "host and guest." In medieval times, hospice came to mean a place of rest for a weary traveler. Hospice care is just that: service and support for patients and their caregivers in the form of medical advice, practical help, and emotional comfort as they take their last journey through life.

Hospice care starts when curative care ends and comfort care begins. A team of clinicians works with the patient and whomever the patient considers to be their caregivers and/or family to create a plan of care that defines what that last journey will look like. The core of the hospice experience is the patient's self-determination; the patient's needs, wants, and worries are what define their treatment. The Inter-disciplinary Group (IDG) is there to advise the patient and/or their caregivers on symptom management – be it physical, spiritual, or emotional-- and to carry out the plan of care. If the team doesn't agree with that plan – for example, if the team feels a patient would benefit greatly from narcotic pain relief but the patient is not in agreement – the patient's choice wins the day. Always.

How Hospice Care Works

Hospice care providers closely follow the "conditions of participation" as defined by the Centers for Medicare & Medicaid Services (CMS) to determine who receives hospice care, and how that care is delivered. With very rare exceptions, EvergreenHealth does not turn away hospice patients, and care is provided no matter what life-limiting condition the patient has. The only requirements are that the patient's prognosis is six months or less, as understood by their physician and a hospice physician, and that the patient or their Designated Power of Attorney (DPOA) elects hospice care. Of course, prognosis is an educated guess, and there are patients who remain on the hospice service for longer than six months. There are also patients who are on service for less than a day.

Hospice care is provided wherever the patient lives. EvergreenHealth Hospice provides care for patients in private homes, adult family homes (AFH-- a group home where up to 6 residents are cared for by trained staff), assisted living facilities (ALF -- a larger facility that cares for patients' everyday needs and, in some cases, provides nursing care), skilled nursing facilities (SNF-- facilities that provide 24 hour supervised nursing care), shelters, and anywhere that an unhoused patient is living.

EvergreenHealth Hospice is also fortunate to be able to provide care at the Gene & Irene Wockner Hospice Center, otherwise known as "the hospice care center" or "the HCC". The HCC is the "hospice hospital" and is housed in a



stand-alone facility located across the street from the east end of the EvergreenHealth Medical Center campus. It has a home-like feel and is surrounded by peaceful grounds. Every room has a door to the outside, and every room has a hummingbird feeder visible from the patient's bed. There are no visiting hours – families are permitted to stay with the patient as much as they would like, and there are two kitchens in which they can prepare meals if desired. Additionally, there are three living rooms that families can use to take a break, or to allow nursing staff to treat the patient privately. Hospice patients are admitted to the HCC if they have symptoms that are challenging to manage without 24-hour nursing care, or if they choose to self-pay to be a “residential” patient.

Every patient is served by an interdisciplinary team. The initial members of the team are the Nurse Case Manager, the Social Work Case Manager, a hospice physician, and a hospice pharmacist. Other services are added when they are deemed necessary and/or requested by the patient. The team can include a certified nursing assistant (CNA) (also known as a Home Health Aide, or HHA) to aid in personal care, a Chaplain to aid in spiritual or existential care, a wound care specialist to treat any stubborn wounds and prevent discomfort or infection, and a volunteer. A patient can have more than one volunteer assigned to them, depending on what volunteer services the patient and team think would be beneficial.

In accordance with CMS rules, patients are visited by a hospice nurse a minimum of every two weeks, and by a social worker a minimum of every 30 days. Most patients are seen far more often than that, with visits gradually increasing as the patient nears end of life. A CNA, if required, typically visits the patient once per week and increases those visits as the patient's ability to perform activities of daily living (ADLs) becomes impaired and their personal care needs increase. The frequency of wound care visits is dictated by the patient's particular care needs. Wound care nurses may visit only once to assess the wound and educate and advise the RN and caregivers on the most effective treatment of the wound or, in the case of more complex wounds, several times a week to provide hands on care. The frequency of chaplain visits is determined by the patient and the chaplain. Field volunteers, who visit patients in their place of residence, typically go once per week. Telephone volunteers, who provide support for caregivers, companionship calls to patients, or call to make sure the patient's medications are well stocked for the weekend, all call once per week.



What Is Hospice Volunteering?

Hospice volunteering is very flexible and is what you want it to be. We currently have 11 defined roles. Maybe you will be the person to come up with number 12!

The Roles

Front Desk: The front desk volunteer is the first person our patients and their visitors meet when they come to the Hospice Care Center. They act as the greeter of the Center,

welcoming all who come through the door, orienting them to the facility, and providing a listening ear when visitors need one. As with every position, each volunteer puts their own stamp on it, depending on their abilities. Some front desk volunteers escort new families through the building, making sure they know where everything is, and sharing some of the history of our facility. Others make sure they are comfortable in the front living room while their patient gets settled. **The one thing all front desk volunteers have in common is a warm smile and welcoming spirit.**

Floor: Floor volunteers work on the units in the Hospice Care Center. They perform a variety of tasks, depending on their interests and abilities. They might be the first to volunteer to make sure a patient's water jug is always full, which allows them to visit briefly with

the patient and/or family. Others might engage with a family in the living room, to give them a break while their patient receives some care. Many see the job as a way to “save steps” for the staff and help with organizing and stocking supplies or running across the street to the hospital to make drop offs or pick-ups. This position suits a variety of volunteers: those who like to be constantly on the move, those who prefer solitary, behind-the-scenes work, and those who are happy to be a gentle presence in a patient’s room, if requested.



Bereavement Phone Calling: Medicare regulations require that we give 13 months of bereavement support to families whose loved one died on our service. Bereavement callers are a crucial part of that support, making two calls to each of our bereaved. The first call is made at the three-month mark, when it feels that most of the world has moved on, but when the grief of the bereaved can still feel very fresh. Our callers connect with the bereaved by phone message, or through conversation. They make sure the bereaved know that we are thinking about them, remind them of our many types of support groups, and are wonderful listeners should the bereaved want to share how they are feeling. A second call, placed by a different volunteer, is made near the anniversary of the patient’s death. This call often has a different feel to it; the bereaved have grown more accustomed to the loss and have found their support systems. The volunteer warmly closes our relationship with the bereaved, reminding them that although we will no longer be reaching out to them, they are always welcome to seek our bereavement services.

If, during either the three-month call or the anniversary call, the volunteer is concerned about the bereaved and how they are coping, the Bereavement Coordinators are notified so that they can follow-up if appropriate.



Bereavement Group Facilitation: EvergreenHealth Hospice’s Bereavement department offers many different types of support groups including anticipatory grief groups, verbal processing groups, spousal loss groups, expressions of grief through creativity or mindful meditation, and purely educational offerings. We are always open to volunteer suggestions for a new type of group. Volunteers can participate in these groups in a variety of ways from setting up the room, providing tech support for virtual groups, or even co-facilitating the group. Depending on the type of group, some previous facilitation experience is strongly desired, and, in some

cases, licensure is required. Participation as a Bereavement Group Facilitator requires extensive additional training and the approval of the Bereavement Coordinators.

Tuck-in Calling: Tuck-in callers place weekly calls to patients in private homes to make sure they have all the medications they will need for the weekend. Although it is sometimes the patient who answers, Tuck-in callers typically speak with the caregiver. Callers speak with the same people week after week. Along with checking on medications, callers ask about pain and comfort, and ask after the caregiver. They remind the family that hospice is a 24-hour service and that they should never hesitate to call us. Tuck-in callers play a unique role on the patient’s care team, and often get to know their patients well enough to be able to alert clinicians to changes in mood or circumstance that the patient might not have disclosed to other members of their team. Tuck-in calls give patients and caregivers peace of mind, connection, and support.

Caregiver Calling: Caregiver Callers are volunteers who are assigned to the patient’s team solely as a support to the Caregiver. Unlike other members of the team, they have no agenda other than to listen to the patient’s support person. They enhance the service that hospice provides to our patients and reaffirm our commitment to treat the entire family unit – the patient and their caregivers. The role of a caregiver can be incredibly stressful and fraught, and it can be helpful for those doing the daily work of caregiving – or those worrying from afar, unable to have routine physical contact with their loved one – to have a friendly, neutral person to speak with.



Field: Our Field volunteers work in a variety of care settings in the community to provide a variety of services in support of our patients and families. They may be visiting a patient to provide companionship. We have had volunteers reminisce with a patient, help them memorialize significant events of their lives in a “Legacy Book,” watch baseball with them, read to them, play music for them, or chat about events of the day. Often, the care setting will dictate the type and length of visit a patient can tolerate. Our patients who are in skilled nursing facilities, for example, often have more acute care needs and can only tolerate short visits. In other settings, there may be patients who are able to enjoy a longer visit. Visits to private family homes are often to give respite to a caregiver (for up to four hours). Those visits may be a mix of companionship and quiet time while the patient rests, or the patient may be resting the entire time. Many field volunteers prefer one type of visit over another. They choose which patients they will visit after reading a short description of the patient: their age, gender expression, diagnosis, and some information about their interests and living situation.



Comfort Touch: Comfort Touch volunteers are licensed massage therapists and/or level 2 Reiki practitioners. They visit patients in the field or at the Hospice Care Center. Touch can be rare at end of life, and our patients find this gentle massage or energy work to be very relaxing and soothing. The work of our Comfort Touch volunteers is invaluable to our patients’ quality of life.

Animal Assisted Therapy: Our dog friends and their handlers are a beloved part of the EvergreenHealth volunteer department. Animal Assisted Therapy teams must be certified by an outside organization and are given site specific training at the Hospice Care Center. They visit weekly and offer their furry support to both patients and their families, and to staff. Handlers report that the dogs often make a beeline to the person in greatest need of support and have witnessed patients who are on the edge of consciousness gently move their hands over the warm coat of their canine visitor.

Office Support: Office Support volunteers assist the Volunteer Coordinators in a variety of ways, depending on their skills and interests. There is always collating, copying, and computer work to be done and our office is a fun and lively place. If you would like to support us through this kind of work, let’s talk. We will work together to find a job that is both meaningful and enjoyable!

Choir: We are delighted and lucky to have a chapter of the Threshold Choir International rehearse and sing here at the Hospice Care Center. The Evergreen Threshold Singers have provided songs of peace and comfort to the residents of EvergreenHealth Hospice Care Center since 2007. The Evergreen Threshold Singers welcome any volunteer who can hold a tune and pitch. There is no requirement to be able to read music. The full group sings in our reflection room, in the halls, and at our yearly Rose Garden Ceremony. Upon request, a smaller group will sing at the bedside.

WHEN AND WHERE?

We ask that our volunteers commit to working with us for a minimum of one year after receiving their badge, for 2-4 hours every week. CMS regulations require hospice volunteers to be thoroughly trained and vetted, which is prohibitive in terms of time and cost if volunteers work with us only briefly. That said, we know you all have lives outside of volunteering. Your regularly planned vacation, or kid's graduation, or any one of the similar life events that give this work meaning take precedence. Go on, live your life, and integrate your volunteering into that, not the other way around! As long as you keep the volunteer coordinators, the teams you are working with, and your patients and their families aware of your absences, we are completely in support of-- and love to hear about-- your rich, full lives!

Each position has its own schedule and routines, and each position has a different time commitment. Hospice Care Center volunteers can take on routine shifts (which are 9AM – 1PM, 1PM – 5PM, 5PM – 9PM/seven days a week, 365 days a year), or can offer to act as a substitute when shifts need covering. Phone volunteers typically work about two hours per week and find that some weeks are full of conversation while others are quieter. Caregiver Callers call their patients on whichever day of the week is mutually agreeable, Bereavement callers work only during office hours, and tuck-in callers work only on Wednesdays.



Field volunteers work in whatever care setting the patient they have chosen is in. They can provide up to four hours each week to each patient. It is up to the volunteer and patient or caregiver to schedule a mutually agreeable time and schedule. A field volunteer may take on more than one patient at a time, and the four-hour time limit can be split up in whatever way the volunteer and patient like. The visits can be much shorter, as well.

Comfort Touch volunteers who work at the HCC find their hours differ depending on how many patients have requested their service. As with all positions, they are encouraged to set their own limits, and not exceed them. On one day, an hour might drain them. The next week, it might be much longer shift.

Animal Assisted Therapy Teams come to the Hospice Care Center on whatever day suits them best. As for how long they visit on any given day, that depends on two factors: how many patients want visits, and how much visiting the dog can tolerate. The needs of the animal must always be paramount. Successful teams are led by handlers who know when their dog has reached their limit.

Office support volunteering is highly variable, depending on the tasks needed to be done. Volunteers should expect to work for about two hours per week.

Choir volunteers meet weekly at the Hospice Care Center for about two hours. They rehearse in our beautiful Reflection Room, sing in the hallways, and, when requested, a smaller group will sing at bedside.

HOW?

How will you do this?

How does a person walk alongside the dying, and support their friends and families? Start by acknowledging that worry, if you have it. Hospice volunteering is probably unlike most things you have done in the past. Your comfort level with death and dying might be unique amongst the people you know. And, although you now find yourself working with like-minded people, you might still be nervous about what it means to accompany the dying and to support their families. The good news is that you are a member of a

team and have the support of the Volunteer Coordinators, clinicians, and managers behind you. More importantly, you stand on the shoulders of every other member of your volunteer village, past and present, and will benefit from their knowledge, experiences, and wisdom much as those who come after you will benefit from yours.

Very few people come to hospice work by accident, and the decision to volunteer is seldom made lightly. To be at the point of reading this manual you filled out an application, asked two people to vouch for you, emailed back and forth with a Volunteer Coordinator, sat for an interview, filled out a lot of paperwork, made time in your schedule, and joined your training class. Taking on those tasks is very intentional and speaks to the fact that you are likely in the right place. If you worry that hospice volunteering might not be for you, chat with one of the Volunteer Coordinators about those concerns. We want happy, dedicated volunteers, and will support you in whatever path you choose to take.

You Will Not Do This Alone. Remember that team we talked about. Every patient has a nurse case manager (RNCM) and a social work case manager (MSWCM). They are here to help you, too. If you are nervous about making a first visit on your own, you can tag along with a case manager. If you have questions about a family's dynamics, the social worker is a wonderful resource. The nurse case manager can help you understand your patient's disease progression. If you are wrestling with some existential questions about death and dying, your patient's chaplain is just the person to talk with. If the loss of your patient brings up feelings of grief, our Bereavement Coordinators will support you. And, always, the Volunteer Coordinators are your champions, your advocates, and your guides.

You Will Not Do This Without Preparation. How is the big question, which is why the rest of manual is dedicated to the ins and outs of "how."

OUR GOALS FOR THIS TRAINING

You are here with intention. Regardless, you might be feeling ambivalent: ready and willing to help, but fearful of putting a foot wrong or of the process of dying. It is very important to us that you feel supported during this training. We are determined that you leave with the information you need to serve your patients well, be fulfilled by your work, and manage the complex emotions that can accompany hospice volunteering. We strive to provide an environment where love, respect, service, and commitment are valued and reinforced. When you successfully complete this training, you will:

Understand that dying is a natural process in the life cycle.

Learn that hospice care provides pain and symptom management, as well as physical, emotional, and spiritual support.

Understand the difference between curative care and comfort care.

Learn to listen without judgment and provide support with compassionate presence. Accept and understand that this is ongoing learning of a lifetime.

Expand your self-reflection and personal growth skills.

Increase your understanding of personal biases and beliefs and how they influence the care you offer to patients and their families.

Increase your understanding of family dynamics.

Understand what "normal grief" is.

Learn to protect yourself and our patients by using infection control standards, understanding and following HIPAA rules, practicing personal boundaries and self-care, and by seeking support from the Volunteer Coordinators, the patient's team members, and the Bereavement department.

Learn the roles of the interdisciplinary team members and how to communicate with them to provide the best possible care for persons approaching death.

Learn the policies and procedures of the EvergreenHealth Hospice Volunteer Program and all its governing bodies.

HOW TO LISTEN

Listening

Think for a moment about listening. Not hearing, listening. What is the difference? Hearing is nothing more than the physiological process of taking in sound. It doesn't require your attention, and it happens without your explicit, conscious participation. If you are having trouble hearing, you might consult an audiologist, who will examine the physical structure of your ear, perform tests to see how your eardrum responds to pressure, and use air conduction to determine the softest possible sound you are able to hear. **Notice that the audiologist uses sounds, not words.** Listening is the world of words – what they mean, what they leave out, what the long spaces between the words are communicating, and how the emotion or intensity of the speaker changes the impact of those words. Listening is active. It requires attention and interpretation. Interpretation means that it is open to bias, which is why truly open and active listening often means asking questions or reflecting and reframing what you have heard. Timing is everything, of course; you can't talk and listen at the same time. Listening can also mean being with another person, and giving them your attention, without any expectation of them and without regard for your perspective. Compassionate presence is the practice of listening with the heart, not the head.

Active Listening

Active listening is respectful and conveys that what is being said is important. Active listeners demonstrate their attention to their conversation partner by using body language; positioning themselves at the same physical level, facing their partner, and maintaining eye contact (if that is comfortable for listener and/or the speaker). They nod frequently, lean into the conversation, and ignore physical and mental distractions. They aren't pulling out their phone every time it vibrates, and they aren't forming counter arguments while the other person is speaking! *Physical cues that you are listening, such as nodding, smiling, showing surprise, or frowning, make it very clear that you are engaged in the conversation.*

Verbal acknowledgment is also important. A simple "hmm," "uh huh," "I understand," or "can you tell me more about that" is a good way to let the speaker know you are interested and would like to continue the interaction. If you are able, without interruption, ask clarifying questions.

Active listeners pay attention to the body language of the speaker, as well as to their tone and emotions. Volunteers working with patients should pay particular attention to signs of distress, such as grimacing, tears, or frowning, and to signs of fatigue, such as the speaker answering more slowly, becoming distracted, or, of course, nodding off. Very few conversations consist of one person talking and the other person only listening. In hospice volunteering, we emphasize that the experience is all about the patient. While this is true, it would feel deeply unnatural to have a conversation in which you were not a participant, at least on some level.

Your role as a listener is to understand what is being said, and to paraphrase it or ask clarifying questions to make sure you understand. Your role as a speaker, in the context of hospice volunteering, is to offer companionship to the patient. If the patient finds a conversational back and forth to be a companionable activity, we invite you to jump in with both feet!

We encourage you to share about yourself, if you feel comfortable doing so, so long as you are not revealing deeply personal information, and if what is shared furthers the conversation. If the patient asks a question, feel free to answer. If you are not comfortable answering, head into every conversation with a strategy to re-direct the chat back to the patient. It can be as simple as saying "I'd like to hear more about your (whatever the question was)." If your side of the conversation is you jumping off from something the patient said and then dominating the interaction with your experience or perspective, then things have gone wrong. It is a very fine line to walk, and one that requires conscious practice. One of our former social workers likened it to successful baking: If you forget to add salt, the end product is bland. If you add too much salt, the end product is inedible. You are the salt.

The Volunteer Coordinators are always available to offer feedback if you are not sure if you have crossed the line, or even where the line is! If you approach your conversations deliberately and thoughtfully, you will do a good job. It can be difficult to set aside judgment or not form counter arguments. It can be difficult not to jump in before your turn if you are excited about the topic. Most of us are not particularly conscious of our behavior as conversationalists, and to pay close attention to it can be humbling. To correct those deficits requires vigilant attention and a dedication to practice. Because guess what? We are all human and none of us are perfect. The good

news is that if your goal is to sincerely hear what the other person is saying, and to share of yourself in an authentic manner, you will be a wonderful conversational partner.

“I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, ‘For someone to look as if they are trying to understand me.’ Indeed, it is impossible to understand fully another person, but I never forgot that he did not ask for success, but only that someone care enough to try.” — Dame Cecily Saunders

Just Listen

“I suspect that the most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention. And especially if it’s given from the heart. When people are talking, there’s no need to do anything but receive them. Just take them in. Listen to what they’re saying. Care about it. Most times caring about it is even more important than understanding it. Most of us don’t value ourselves or our love enough to know this. It has taken me a long time to believe in the power of simply saying, “I’m so sorry,” when someone is in pain. And meaning it. A patient told me that when she tried to tell her story people often interrupted to tell her that they once had something just like that happen to them. Subtly her pain became a story about themselves. Eventually she stopped talking to most people. It was just too lonely. We connect through listening. When we interrupt what someone is saying to let them know that we understand, we move the focus of attention to ourselves. When we listen, they know we care. Many people with cancer talk about the relief of having someone just listen. I have even learned to respond to someone crying by just listening. In the old days I used to reach for the tissues, until I realized that passing a person a tissue may be just another way to shut them down, to take them out of their experience of sadness and grief. Now I just listen. When they have cried all they need to cry, they find me there with them. This simple thing has not been that easy to learn. It certainly went against everything I had been taught since I was very young. I thought people listened only because they were too timid to speak or did not know the answer. A loving silence often has far more power to heal and to connect than the most well-intentioned words.”

—Rachel Naomi Remen, Kitchen Table Wisdom

COMPASSIONATE PRESENCE; LISTENING WITH THE HEART

“Compassionate presence” is a phrase you will hear often during your volunteer work with EvergreenHealth Hospice. Think of compassionate presence as a model for listening. At its heart, compassionate presence is companionship that is not hierarchical, that does not judge, that does not attempt to alleviate or solve, and that honors the agency of the speaker over the needs of the listener. Compassionate presence is actively and intentionally being with another person.

Compassionate presence is:

Paying attention.

Looking clearly at and being mindful of the present no matter how painful.

Letting go of pre-conceived notions. Being adaptable and not attaching to outcomes.

Being comfortable with not knowing.

Trusting the internal resources of the speaker and knowing that each of us has our own answers.

Being authentic. Showing up as you are, without worrying about how you are perceived.

Being present with another person’s pain. Knowing you cannot take it away or resolve it. That is not your responsibility, your right, nor your privilege.

Honoring the spirit vs. focusing on the intellect.

Curiosity vs. expertise.

Learning from others vs. teaching them.

Walking alongside vs. leading.

Being still vs. moving.

Discovering the gifts of silence vs. filling every moment.

Listening with the heart vs. analyzing with the head.

Bearing witness to the struggles of others vs. judging or directing those struggles.

Being present with another person's pain vs. trying to take away or relieve the pain.

Respecting disorder and confusion vs. imposing order and logic.

Going into the wilderness of the soul with another human being vs. feeling responsible for finding the way out.

Compassionate presence can also be described as "listening from the heart," which this exasperated and anonymous author explains very well:

"When I ask you to listen to me and you start giving advice, you have not done what I asked. When I ask you to listen to me and you begin to tell me why I shouldn't feel that way you are trampling on my feelings. When I ask you to listen to me and you feel you have to do something to solve my problem, you have failed me, strange as that may seem. Listen! All I asked was that you listen, not talk or do – just hear me. Advice is cheap. A quarter will get you both Dear Abby and Billy Graham in the same newspaper. And I can do that for myself. I am not helpless. Maybe discouraged and faltering, but not helpless. When you do something for me that I can and need to do for myself, you contribute to my fear and inadequacy. But when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I can quit trying to convince you and can get about the business of understanding what is behind this irrational feeling. And when that's clear, the answers are obvious and I don't need advice."

Be Attitudes

Caregiving means giving the most special gift we can: ourselves. Our presence is all that is needed when the gift of being is mutually exchanged.

"If we want to support each other's inner lives, we must remember a simple truth: The human soul does not want to be fixed; it simply wants to be seen and heard. If we want to see and hear a person's soul, there is another truth we must remember: The soul is like a wild animal; tough, resilient, and yet shy. When we go crashing through the woods shouting for it to come out so we can help it, the soul will stay in hiding. But if we are willing to sit quietly and wait for a while, the soul may show itself." — Parker Palmer, The Courage to Teach

Be Prepared

Caring for someone requires preparation. Give thought to how you will care for yourself so that you might be of service to others.

Be Present: Quiet your soul and let go of all concerns so you can be fully present with someone.

Be Open: Accept people as you find them, without conditions. Allow them to be who they are without judging them.

Be Still: Listen, listen, listen! Listen without looking for answers or solutions.

Be Trustworthy: Speak and behave in ways that show giving, not taking. What vulnerable people need most is someone they can trust.

Be Sensitive: Try to understand needs, concerns, and fears. Listen between the lines and ask questions that help the person share their concerns.

Be Human: Know that you can identify with the person's feelings, but that you are not inside their experience.

Be Honest: Admit that you don't have all the answers.

Be Supportive: Find ways to give encouragement and help when you can. Try to leave the person reassured by your presence.

Be Silent: There is no need to fill all the silent moments. Hold their hand. Be with them.

Be Empathetic: Do the best you can to put yourself in their situation. Feel with the person, not about them.

Be Compassionate: Convey your care in both words and deeds. Be tender, tolerant, considerate, and gentle.

Be Yourself: Allow the person to know you. Allow humor to surface when it feels right.

Be Respectful: Respect diversity of beliefs and opinions. Allow for different needs and different practices.

Be Spiritually Responsive: Follow the person's lead and allow your spirit to be in communion with theirs. This may mean sharing readings from scripture or other sources if requested or praying when given an invitation. Participate with kindness and an open mind if these are not your practices.

The Art of Being

"The art of being is the assumption that you may possess this very minute, those qualities of spirit and attitudes of mind that make for radiant living. It is a philosophy of being today. It is recognizing that courage; joy, serenity, faith, hope, and love are immediately available now. It is being great now, being forgiving now, being tolerant now, being happy now, being successful now, instead of postponing positive and constructive living to some vague and indefinite future. It is beginning today to be the person you want to be. It is developing an awareness of the infinite possibilities in each magic moment. It is not easy to stop and be present. Our sense of presence is the most powerful gift we can offer, and in turn, we can draw out that quality in others. There is tremendous value in simply being able to sit still and be with another person without pretense. Being present has a quality of stability that can communicate in the midst of activity as well as when we are sitting still. No matter what is swirling around, no matter how chaotic or difficult the situation, the sense of presence is a stabilizing force. When we lost contact with what is going on, we can touch back in through that sense of presence. It is completely reliable...like the earth."-- Judith L. Lief, Making Friends with Death

Compassionate Presence

From the May 2008 newsletter by Linda Loba: After reading what Melissa mentioned about compassionate presence, it struck me as such a special skill. I asked Mary Hejnal for her thoughts on the subject [a former employee who taught Compassionate Presence at Core Training], and she kindly loaned me her notes and a book titled "The Art of Being a Healing Presence" by James E. Miller to help me explore this topic further.

The title on Mary's notes is "Compassionate Presence: A Model for Listening" and listening seems to be the foundation for Compassionate Presence. This idea of listening applies to a broad range of situations. There is listening when someone needs to tell their story; when someone is trying to find answers; or when there is no talking at all – but you are listening anyway, to unspoken messages from the person you're sitting with or unspoken messages you may be receiving from inside. It is all so very subtle, and the idea of being mindful, fully present to the situation, is crucial. This is where the "Presence" in Compassionate Presence comes in. The word "presence" in this context is filled with meaning, and what follows, from Mary's notes, illustrates this: "Compassionate Presence is paying attention. Open yourself to the moment; your level of awareness is your most valuable tool. Listen with your whole body, even when there are no words. Maintain eye contact to show that you are truly there with the person. Compassionate Presence is looking clearly at and being mindful of what is happening right now. Listen with your heart (not your head) to the words and the feelings being expressed. Avoid thinking about what you might say next, or how you can help take away this person's pain. Remember: it is not about you.

Compassionate Presence is being adaptable, and not attaching to the outcome. Plan ahead but be ready to adjust to whatever is happening in the moment. Meet the person right where they are.

Compassionate Presence is creating space for not knowing. All the degrees and theories in the world cannot compete with a listening heart. This also helps to not attach to the outcome. Trust the process: in the silence of listening, healing occurs.

Compassionate Presence is trusting the internal resources of the person; knowing that each person has his or her own answers.

Compassionate Presence is being yourself. This is where authenticity and integrity rule. Being real gives others permission to be real right back. And it's ok to say "I don't know..." Compassionate Presence is being present to another person's pain and not thinking you have to take it away."

In not turning away from the pain, we can manage to hold it – we become the container. As Mary says, "If I am thinking there is a

problem to be solved, I am not listening with my heart.” (And, as you hold that person’s story, maintain a mindful setting of personal boundaries. You can hold their story without actually “owning” it.) Compassionate Presence includes the heart. It is about creating space within to hear, feel, and be totally present. It is about coming from the ground of your own being to be optimally helpful to another.”

In the book *Mary loaned me*, it is mentioned that we don’t do presence, we are presence. We need to enter the situation clear and open, silencing the chatter in our minds, leaving all personal agendas at the door. If the other person wishes to talk, listen thoughtfully, nodding from time to time, maintaining eye contact. On the other hand, don’t feel uneasy if there is silence; a lot of answers can be found in silence.

“At the end of day, fashion a Compassionate Presence that is your very own. As the book says, ‘healing presence is an art, not a science...artists [make] their work personal and distinctive, combining their intuition and vision with their gifts and skills to create something uniquely theirs. We are invited to bring our uniqueness, our depth, and our fullness to this creative undertaking...’ And if you find that you feel you’ve somehow “failed,” accept the fact that you’re going to make mistakes and offer yourself compassion with the knowledge that your intentions to help are sincere and that your skills will improve with experience. Be present in simplicity, be present with willingness, and be present with gratitude. More than anything, just be...”

WE HONOR VETERANS

EvergreenHealth is proud to work with We Honor Veterans, a program of the National Hospice and Palliative Care Organization (NHPCO) in collaboration with the Department of Veterans Affairs (VA). The program is focused on respectful inquiry, compassionate listening, and grateful acknowledgment. By recognizing the unique needs of America’s Veterans and their families we learn how to accompany and guide them through their life stories toward a more peaceful ending.

“The outcome of any armed conflict holds not just the promise of peace but also dark, terrible revelations, questions of justice over the vanquished, and, for far too many, the confronting of personal loss.” Veterans History Project – Forever a Soldier: Unforgettable Stories of Wartime Service

Every veteran is a unique person with particular needs. Although all veterans are a part of military culture, every veteran’s experience of their service is different. They may have served stateside; they may have been stationed in a foreign country very far from home. The veteran might have been in combat (and every combat situation has its own challenges) or have worked in an administrative or support capacity. As with everyone, the veteran’s ideals, beliefs, and demeanor are shaped by the totality of their life events. For some veterans, their time in the service is long behind them and mostly forgotten. For others, it is the defining event of their life. Assuming that non-combat veterans will have fewer needs is as unrealistic as assuming that all combat veterans will have many.



We Honor Veterans is designed to empower hospice professionals to meet the needs of dying veterans.

Approximately 25% of people dying every year are American Veterans

1800 Veterans die every day

Only 33% of Veterans receive VA benefits

Only 4% of Veterans die under the care of the VA

Your patient may be a Veteran and may need a particular approach. Much of the advice below applies to any patient but is of extra importance when supporting our Veterans.

Give Veterans an opportunity to tell their stories.

Respect their military service and their feelings about that service.

Show appreciation for the families of Veterans. Families serve, too.

Always be sincere, caring, compassionate, and ready to listen to what a Veteran or family member has to share. Be supportive and non-judgmental, always validating their feelings and concerns.

It might take longer for Veterans to trust you. Be patient and listen. Don't push the relationship.

Expect the Veteran's sharing to occur over a period of time, not all at once.

If a Veteran wants to share their story and express emotions, be prepared to give comfort and reassurance. Even if you have a lived through a similar experience, don't say "I know how you feel." Instead, you might say something like, "It must have been very difficult for you."

Many of us aren't quite sure how to talk about experiences we have not had. What not to say to your Veteran patient:

Did you kill anyone?

Did you see the news?

Do you feel guilty about what you had to do during the war?

Anything about current conflicts or military politics.

What was it like over there?

I do not know anything about what you are going through. I have never served.

Do not tell a Veteran that you understand what their experience. If they want to talk, ask open ended questions.

Do not tell a veteran they should be grateful that they made it home alive.

Veterans' Unique Health Risks

Veterans of different wars have unique physical and mental health risks, based on where they served, the weaponry that was used, and the numbers of casualties they might have witnessed. There may not be visual indicators of what a veteran has gone through. Different wars or locations of service may bring specific, unique injuries that may or may not be obvious.

WWII/Korea: Cold injury, Chemical warfare agents, Exposure to nuclear weapons (including testing and cleanup)

Cold War: Nuclear testing

Vietnam: Agent orange exposure, Hepatitis C

Gulf Wars: Chemical or biological agents, Dermatologic issues, Exposures to smoke, Infectious diseases, Reproductive health issues

Operation Enduring Freedom, Operation Iraqi Freedom, Operation New Dawn: Blast injuries, Dermatologic issues, Reproductive health issues, Vision loss

Veterans' Unique Needs

America's Veterans -- and their loved ones -- may have unique needs influenced by:

- Combat or non-combat experience
- The war in which they served
- If they were prisoners of war (POWs)
- If they experienced or continue to experience post-traumatic stress disorder (PTSD)
- Their branch of service and rank
- Whether they were enlisted or drafted
- Their age when they served

Traumatic Combat Memories Can Cause:

- Alcohol and drug misuse
- Social isolation
- Anxieties
- Outbursts of anger
- Difficulty concentrating
- Post-Traumatic Stress Disorder (PTSD)
- Guilt and shame

First and foremost, not every Veteran will have unique needs, so we must make sure that we do not make assumptions based on the title of "Veteran." Many influences can shape a Veteran's ideals, beliefs, and demeanor. Combat and non-combat experiences both influence a Veteran's needs. Their needs may be equal for either case, but assumptions of combat Veterans having more extensive unique needs, while non-combat Veterans have little to no needs, is unrealistic. The paranoia and stress placed on a non-combat Veteran could be the initial onset for specific needs that the Veteran now requires. The magnitude and time spent in a specific war is a major factor in determining needs of Veterans. More than likely, Prisoners of War (POW's) may have experienced a higher level of trauma from their war experiences, which could increase unique needs of that specific Veteran. Those Veterans who had, or currently struggle with PTSD, may require a more extensive level of support in relation to their needs. Depending on the war or conflict that the Veteran took part in, the specific branch and rank may have suffered more casualties during the war, which could be an indicator of increased needs. While enlisted Veterans might have specific needs, drafted Veterans may be bitter about their forced military service. This can increase the needs of drafted Veterans and may also make the task of supporting that Veteran slightly more difficult. Why is it Important to have Volunteers Identified Specifically for Veterans? They share a common language and code of conduct.

Veteran volunteers understand of military culture and have experienced similar societal reactions.

Their common life experiences may help establish trust and supports life review and healing for the Veteran patient.

The Veteran patient knows that Veteran volunteers understand and listen without judgment.

How can Non-Veteran Volunteers participate? Hospice volunteers without a military history can also support Veterans at end of life, particularly those who:

- Have family members who served.
- Were raised in a military family.
- Have worked closely with the military as a civilian.
- Are employed in an organization that serves Veterans.
- Identify Veterans as an underserved population.

Are committed to no Veteran dying alone.

Are willing to learn about the unique needs of Veterans.

Military Cultural Norms: The Military is a unique culture, dependent on shared assumptions.

If you haven't been there, you won't get it

Loyalty

Camaraderie

Teamwork

Discipline

Suppression of emotions: Military training revolves around the central idea that emotions are a weakness that can compromise the success of the mission. Accordingly, soldiers are taught to suppress any fear-based emotions. Many Veterans who have adopted this military cultural norm in a time of war may find it find themselves behaving in the same way when faced with the challenges of end of life and impending death.

Types Of Response To War Trauma

Three responses to war trauma: Integrated Response to Trauma

The trauma has been processed, often with professional help

Healing occurs and life goes on

Incomplete Integration of Trauma

PTSD is prolonged

Apparent Integration of trauma

Trauma is kept in the subconscious

Everything seems to go on but there are lingering effects of war trauma (Trauma is undiagnosed or has a delayed onset).

Possible Outcomes from Combat Experience: Veterans integrate their service experience into their lives to varying degrees. Some factors that may help:

They are resilient

They have good family and social support

They had a positive war outcome

They talked about their war experiences

Integrated Response to Trauma: It's important to:

Listen carefully

Invite them to tell their stories

Express appreciation for their service to our country

Celebrate their accomplishments with them

Affirm the wisdom they have gained and let it impact your life

These statements show some effects that trauma can have on a Veteran. It is very important that you, as a Veteran volunteer, remember the most important guidelines when dealing with other Veterans. These include listening carefully to anything that the Veteran says, expressing sincere appreciation for the Veteran's service, celebration of accomplishments, and affirmation of the wisdom that the Veteran has gained, which may leave an impact on your life.

Incomplete Integrated Response to Trauma: Indications of a Veteran with incomplete integrated trauma include:

- PTSD
- History of alcohol and/or drug abuse
- Estranged relationships
- Unfulfilled longings
- Suspicion & lack of trust
- Anxiety and agitation or acting out of the trauma
- Nightmares
- Staying “on guard”



If you hear any of these statements or notice any of these symptoms, notify the Volunteer Coordinator immediately.

Responding to Stoicism: Create safe emotional spaces for tears and fears by validating feelings: “It’s only normal that you might feel sad right now. It’s okay to cry.” “Most veterans tell me that they feel a little afraid at a time like this.”

Responding To Guilt: Hear It & Get Help

FORGIVENESS! FORGIVENESS! FORGIVENESS! Guilt should be taken seriously and assessed. It should not be dismissed with platitudes. Forgiveness is the cornerstone of healing. Feeling healed or absolved is important for a good death.

“Veterans may come before us acknowledging the pain that they have caused others. That they have killed. That they have maimed. That they hurt with the pain of knowing they did this. They hurt with pain for humanity. They come before us now asking for forgiveness. They need mercy to restore their integrity. They come before us saying “Forgive me for the wrongs I have committed”. Forgiveness can restore them to wholeness.” – Adapted from a prayer

There may be a need for forgiveness around:

- Self (for actions taken in war, killing)
- Self (for not killing, not dying, “friendly fire”)
- Government (using/betraying them in Vietnam)
- The World (for being as it is)
- God (for allowing the world to be as it is)

Family Dynamics And The Dying Veteran

The spouse or family may have resentment due to the Veteran being away from home and/or the Veteran has too high expectation from spouse/family and/or the Veteran may feel rejected because of spouse or family’s attitude toward him.

The Patient

Imagine yourself in this experience: You have been receiving treatment for cancer, off and on, for many years. Although unpleasant and stressful, it has almost become routine. You know the staff who administer your chemotherapy well and have even marked life events with them – birthdays, grandchildren arriving, moving. You are used to the rhythm of treatment: long breaks when your disease is under control interrupted by new and concerning symptoms followed by a scan being ordered and your treatment adjusted.

Until the day when there are no more adjustments to be made. In the back of your mind, you knew this day might come, but you had been through this sequence of events so many times it was starting to seem as if it would just continue forever. The possibility of no more interventions seemed remote. That there are no treatment options left is genuinely shocking and upsetting to you and your loved ones. After you are told the news, you are not able to take in the rest of what your doctor is saying.

You are advised to seek hospice care, which you have heard of, but don't know much about. The doctor explains it to you, but the entire experience is overwhelming, and you only have a vague sense of what you are being told. You are given a brochure and sent home. Within a few days of making the decision to call hospice to set up an appointment, the intake team arrives at your house. They are kind, calm, and reassuring, but they are also giving you a lot of new information, asking a lot of questions (many of which you have answered over and over during your care), explaining how the hospice system works, and having you sign many forms.

You are asked to make decisions about your care and your end of life that you might not have contemplated before. Although you are assured that you can re-visit those decisions if your thinking changes, simply contending with them is a profound experience. The appointment is several hours long, and by the end you are exhausted. Concerned family members are waiting by their phones for an update and neither you nor your caregiver have much energy left to call and reassure them.

After assessing your condition, the hospice team orders supplies, equipment, and medications. Some of it arrives the next day. Not only is your idea of the rest of your life upended, but your physical space is also. For both you and your family, your fate is made even



more real when a hospital bed is placed in your living room, as you are advised not to attempt stairs any longer. Your caregiver needs to find space to store personal care items (briefs, pads for the bed, various cleaning items) while trying to keep your home from feeling like a hospital. You are horrified to see that a bedside commode has been delivered, but glad not to have to make your way to the bathroom, which suddenly feels very far away.

Everything has changed, in what feels like the blink of an eye, and you haven't even met your team yet.

It is a relief when you meet your social worker. They are patient, and they reassure you when you are embarrassed to realize you have asked the same question more than once. There are a lot of details to finalize, but the social worker walks you and your caregiver through them and works at your pace. When they tell you that you can call hospice whenever you need to, you know it is a genuine



offer. Your visit with your nurse is equally gentle. They are knowledgeable and dispel some of your fears by asking a lot of questions, and listening to what you want. When you tell them that it is important to you to be as alert as possible, they discuss the different options for managing your pain – the pluses and minuses of each choice – and help you decide on your plan of care. They talk with you about which medications you can stop taking, and why, and explain what to expect next. Your caregiver has some questions about how to best help you out of bed and to your favorite chair, and the nurse teaches them how to transfer you while keeping everyone safe. You start to feel better about what is to come, and after a few days on the new medication regime, you perk up a bit. Your appetite even starts to return.

Despite feeling better, you are still more tired than you have ever been, and it is difficult – impossible, really – to take proper care of yourself. Your social worker and nurse suggest that a certified nursing assistant be added to your team. Although your caregiver has been doing a very good job of helping you up until now, your lack of mobility and their lack of training mean the possibility of injury for each of you is high. The case managers explain that knowledge of proper body mechanics and experience with bathing patients who are bedbound are very important to avoid injury or falls. A weekly CNA visit is ordered. You are embarrassed and dreading it. You do not want to be bathed by a total stranger.

When the CNA arrives, you feel a bit shy, but they are friendly and respectful, and work at your pace. They explain what they are going to do before they do it and are experts at putting

your dignity first. You quickly forget your discomfort. When they have finished helping you with bathing and grooming, you feel clean, fresh (and tired!), and in a very good mood. You quickly come to look forward to their visits. Your caregiver is also greatly relieved; the CNA teaches them how to provide as much care as they can for you, safely.

Over the next few weeks, you get to know the volunteer who calls you every Wednesday to make sure you have all the medications you need for the weekend. Sometimes you talk to them, sometimes your caregiver does. You always appreciate that they ask how you are feeling and if you have any pain. Your caregiver feels supported when the caller sincerely says “taking care of your person is a big job. How are you doing?”

Your caregiver is working very hard to figure out the new ways you need to be cared for and doesn't have much time for themselves. When you mention this to your social worker, they suggest having a volunteer come to the house to give your caregiver a break. When you quietly let them know you would be embarrassed to have a volunteer take on some of your caregiver's roles, they assure you that the volunteer is there to keep you company and make sure you are safe. Personal care is left to the caregiver or the CNA. They put in a request, and a few weeks later, you have a friendly volunteer visiting the house so that your caregiver can run some errands. You thought it might be a bit awkward to have a stranger in your house, but you pass the time happily chatting about your shared interests, reminiscing about your life, and snoozing (your volunteer brought a book with them, just in case you wanted some quiet time).

You and your team have settled into a routine. You do not have to worry about your care. This leaves time, however, for you to do a lot of thinking. You find yourself wondering what it really means to have your life draw to a close. The grief and fear of the unknown can seem unbearable. You do not want to burden your family with your anxieties. You remember that at some point you were offered visits from a chaplain, but you said "no thank you" as religion had never been a part of your life. You decide to see what talking with one of them might be like, and your social worker puts in the request for you.

It turns out that visiting with a chaplain isn't at all what you expected. It is time spent with one of the best listeners you have ever met. They don't read from the bible or talk about God because your social worker has told them that is not what you want. The chaplain doesn't have answers to your difficult questions, but they are not shocked by them. You never thought you could have such a matter-of-fact conversation about death. You always feel calm after their visits.

Although you would much rather be out and about in the world, you know that is no longer possible. Your mind is put somewhat at rest thanks to the thoughtful care you are receiving. You feel relieved to have so many professionals looking after you and appreciate that they are also taking your caregiver's circumstances and needs into account. As your disease progresses, you can focus your attention on what matters: time with family and friends. Eventually, your pain is more than you can bear, and your team, listening to what you want and need, increases your pain medication. You can't really stay awake for very long. With their support, your mind is at ease, and you are finally able to allow your body to be at rest.

SPIRITUAL ISSUES IN THE CARE OF DYING PATIENTS

End of life is a time of self-examination, which naturally leads to many existential and spiritual questions. Spiritual needs-- questions of meaning, value, and relationships – often become more pronounced as a patient faces their mortality with a new urgency. Overall quality of life, particularly as one's life draws to a close, is highly correlated with spiritual and existential well-being. Spirituality, in this respect, is broader than religion. While not everyone has a religion, spiritual issues arise for almost all who are dying. Theology, religion, and spirituality are not necessarily the same. Some of us identify as both religious and spiritual; some as spiritual but not religious. Spirituality is about how one interacts with transcendent and philosophical questions about what it means to be human, and to have lived a life with meaning. Religion takes up those same questions, guided by a set of texts, practices, and beliefs shared by a community.

Spirituality is what brings meaning to our lives. It can be found in the connections we have with people, animals, or nature. It lives in our choices, our values, our priorities. Spirituality is our hopes for the present, and our hopes for what transcends the present. Spirituality can come from the comfort of the known, and from our openness to new experiences. How we are is so much more important than what we say or do. Hospice work, and being a hospice patient, can lead to deep self-reflection. It can refocus what we consider "meaning", enhance our values, encourage new choices, and change outlooks. Spirituality evolves. Those who work with the dying often witness families and patients:

Attempting to understand and transform suffering.

Experiencing the spiritual pain that is the result of unwelcome deconstruction of meaning and purpose.

Searching for new meaning and purpose.

Trying to make connections and heal relationships.

Attempting to understand the mystery of death.

The dying may want to know if there is any meaning in suffering or dying. They might be contending with the despair of a lifetime of disappointment, fractured relationships, and personal regrets. Spending time with that hopelessness can be transformational, and the patient – with the help of spiritual care – can come to find profound learning from it. Relationships can be repaired or recontextualized. Disappointments and regrets can be powerful teachers full of value upon reflection. Regardless of religious affiliation, the need of the dying to understand that they are treasured and cherished – that their time on earth had meaning to them and to others-- is a powerful example of spirituality.

Facing the end of life and shifting roles can profoundly affect a person's sense of dignity. Although dignity – being worthy of value and respect – is intrinsic to being human, it is also a concept that is often loaded with judgment in our modern context. Our culture is not always good at recognizing dignity as something all people possess. It is often something thought of as being “earned.” People who are dying might need reassurance that their complete dependence on others, reduced productivity, and changing appearance do not affect their value as human beings. It is not the task of the health care team to give patients meaning, value, or reconciliation, but to facilitate patients' encounters with the meaning, value, and relationships that are already present.

Spiritual Issues Raised At The End Of Life

Questions of Meaning:

“What is the meaning of my illness?”

“What is the meaning of my suffering?”

“What is the meaning of my death?”

“Will any meaning persist beyond my death?”

Questions of Value:

“How does my value relate to my productivity, my appearance, my independence?”

“What is valuable about me when these are threatened?”

“Is there anything valuable about me that will persist beyond death?”

Questions of Relationship:

“What does my estrangement from family or friends mean?”

“Who have I wronged? Who has wronged me?”

“Am I loved? By whom?”

“Does love endure beyond the grave?”

You, of course, do not have the answer to these questions. They are not your questions to answer. Your best response to the spiritual needs of your patients is to pay respectful attention to their ultimate concerns. Be present with them, show that they are worthy of time and attention, and listen deeply to what the dying can teach about life and its meaning.

Spirituality, Hospice Care, And The Volunteer: As a volunteer supporting others at end of life, you are reminded that death can come at any time. We all have chances, due to unwanted changes, losses, or other painful circumstances, to contemplate deep spiritual questions. Undertaking that work is good for everyone. The volunteer gains a deeper understanding of themselves, and of our hospice families. Doing the work yourself makes it easier to understand what that experience can be like for patients and their families. In doing this work, we bring meaning to our lives by having made a difference in the world and in others' lives. We offer:

Openness without expectation

Generous listening

Staying the sadness and distress of another

A sense of playfulness and humor

Genuineness about who we are

Our journey through life is made spiritual by:

Developing a good heart

Seeking the greater good

Realizing our own wisdom

Being playful, generous, and kind thereby bringing goodness into the world

End-Of-Life Developmental Milestones And Tasks: Dr. Ira Byock is a leader and educator focused on promoting quality care at the end of life. He developed a framework to categorize some of the issues that many contemplate as they approach death. Dr. Byock's findings offer a holistic understanding of the dying process. The journey toward death can be a time of new insights, personal growth, and inner healing. The experience of dying may include:

A sense of completion with worldly affairs

A sense of completion in relationships with community

A sense of meaning about one's life

A sense of meaning about life in general

Experiencing love of self

Experiencing love of others

A sense of completion in relationships with family and friends

The acceptance of the finality of life and of one's existence as an individual

A sense of a new self beyond loss

A surrendering to the transcendent and to the unknown

A feeling of letting go

Hospice Spiritual Concerns

In expressing the need for personal spiritual help the patient may demonstrate

Spiritual suffering they can't explain

Struggling to maintain comfort, peace, hope, and trust on their own

Expressing an inability to cope with their situation

Being focused on questions such as "why me?"

Expressing, either directly or metaphorically, anxiety or insecurity

Signs or direct expression of despair, hopelessness, and apathy

Preoccupation with feelings of guilt, shame, fear, regret, worthlessness, or unworthiness

Need for relational spiritual help

Worries about unfinished business-- with self, others, God, or institutions

A lack of trust, either general or specific to certain relationships

The fear of being alone or of dying alone

A need to give and receive love

Expressions of loneliness, isolation, or rejection

Feeling separate or alienated from their support network or community of faith

Ambivalence or anger toward God

Need for broad spiritual help

A search for meaning, purpose, values that has escalated to a crisis

Speaking of a lack of objectives, goals, or hope

Openly questioning meaning of life, illness, suffering, or death

A need for symbolic expression—rituals, sacraments, etc

What do you think has become of the young and old men? And what do you think has become of the women and children? They are alive and well somewhere, The smallest sprout shows there is really no death, And if ever there was it led forward life, and does not wait at the end to arrest it, And ceas'd the moment life appear'd. All goes onward and outward, nothing collapses, And to die is different from what any one supposed, and luckier. Walt Whitman, Song of Myself, 6

FAMILY SYSTEMS THEORY

Call it a clan, call it a network, call it a tribe, call it a family. Whatever you call it, whoever you are, you need one. — Jane Howard

The family is a unit or a system where there is absolute interdependence. Anything that affects an individual affects the whole family. Unconsciously, families adopt strategies to maintain balance and equilibrium. Think of the family as a mobile. When you move one branch, all of the other branches are affected, in their own way. Ultimately, every branch resettles and returns to its starting position. This is why, despite time, distance, and different life experiences, the baby is still the baby, the organizer is still the one handing out jobs, and the worrier is the one trying to take care of everyone else.

“Thou canst not stir a flower without troubling of a star;” — Francis Thompson, The Mistress of Vision

There are two basic types of family systems. Open and closed.

Open Family System: One hallmark of open families is a direct communication style. They speak to one another clearly and without judgment. Conversation happens out in the open, as a means to understanding. Family members do not talk behind one another’s backs, or triangulate to “win” a conversation. Open families can talk about the most sensitive topics without fear of being shamed or shunned. Flexibility is the operating principle of an open family. While there are overt (and therefore comfortably predictable) rules, there is an understanding that change is normal and inevitable. Change is accepted and supported with flexible roles and boundaries. For example, a change in identity. In an open family a child who shares that they are transgender would experience no change in their familial roles. Yes, there might be questions and conversation, but they would be in the service of understanding the child’s experience and supporting them as they navigate their selfhood. If the child brought home a new partner with them, the partner would be welcomed, and the relationship celebrated.



Closed Family System: Closed families do not communicate with one another clearly or directly. They are more prone to talk about one another than to one another. Comments can be indirect, unclear, and inconsistent. This can create misunderstandings, distrust, and encourage secret keeping. Similarly, family rules are covert. Unspoken agreements about what information is shared and with whom abound. Boundaries amongst closed family members tend to be enmeshed. There, the family unit takes precedence over the needs of the individual. Decisions can be difficult to make as there are many perspectives at play. Roles in closed families are unspoken and inflexible. Regardless of a family member's desire to play that role, it is theirs for life. For example, if one person has always organized the holidays, it is nearly impossible for a new person to come in and take on the task. The person who is typically the family communicator will be the one who others turn to for information. The "fixer" will always put things right, and those who rely on them will not be able to learn or practice those skills. A closed family struggles more with change; they follow the same rules they always have, even if those rules are no longer appropriate. This might be a family unable to alter holiday traditions, for example, even if everyone's life circumstances make it difficult to get to Grandma's house every Thanksgiving. The inability to accept growth and change might lead to negative feelings or even estrangement.

Communication Patterns

Open – closed

Direct – indirect

Verbal – nonverbal

Acceptance – prohibition of expression of feelings

Consistent – inconsistent behavior

Validating – disqualifying messages

Boundaries: Flexible – rigid, Permeable – impermeable, Enmeshed – disengaged

Roles: Flexible – inflexible, Can one member's role be assumed by another? Role reversal

Rules: Overt – covert

Alliances and coalitions: Dyad – triangle – subsets

Opposing Tasks: Supporting a dying loved one often requires families to work toward goals that are seemingly in opposition to one another. For example:

Holding on to the patient while letting go.

Increasing attachment to the patient during the illness while starting to detach from the patient in terms of her or his existence in the future.

Remaining involved with patient while separating from the patient.

Planning for life after the death of the patient while not wanting to betray the patient by considering life in her absence.

Communicating feelings to the patient while not wanting to make the patient feel guilty for dying or bound to this world when the patient needs to let go.

Balancing support for the patient's increased dependency while supporting the patient's continued need for autonomy.

Redistributing family roles and responsibilities while not wanting to do anything that would call attention to or cause more losses for the patient.

Taking care of the patient's needs while taking care of one's own needs.

Experiencing the full intensity of the feelings involved in anticipatory grief while trying not to become overwhelmed.

Focusing on the patient as a living person while remembering that the patient is dying.

PAIN AND SYMPTOMS AT END OF LIFE

Bill Of Rights For People With Pain

Pain and pain management can be thorny topics. Pain shows up differently in each person and is understood through very personal experience. To believe that a person is intense pain when it manifests differently in each individual can be difficult. One person might grimace at a “small” amount of pain, while another will appear stoic despite describing their pain as intense.

Until you or a loved one experiences significant pain that requires intensive treatment your only exposure to-- or understanding of -- narcotic medications might have come from overwrought reporting on the nightly news. As a result, some of our most potent treatments for pain are associated with social stigma and conditions that are poorly understood and easily judged. There are no features on the nightly news talking about how effective morphine is in treating air hunger, or that fentanyl is the only thing that relieves the suffering of some patients and allows them peaceful time with their families.

This Bill of Rights for People with Pain was developed to encourage patients, their loved ones, and caregivers to learn about pain and its treatment. Knowledge, clear communication, and caring are needed to ensure the best pain relief available.

I have the right to be believed by health professionals, family, friends, and others around me. The person in pain is the only one who knows how much pain they have. Patients should be encouraged to report and describe their pain as accurately as possible. Healthcare professionals need to acknowledge that stoicism, reluctance to take drugs, cultural beliefs, feelings of resignation, and other factors often inhibit patients from talking about their pain. Patients and their providers need to work collaboratively to understand these obstacles to accurately assess pain.

I have the right to have my pain controlled, no matter what its cause or how severe it may be. Pain must be understood, as well as believed. In recent years, major advances have been made in understanding pain and its effective treatment. The health care team must consider all information and resources necessary to make patients as comfortable as possible.

I have the right to be treated with respect. When I need medication for pain, that does not mean I have a substance use disorder. Healthcare professionals, the public, law enforcement agents, and even people in pain often believe that using pain relieving drugs will lead to addiction. Yet this almost never happens. Disordered use of drugs is unrelated to the use of drugs for cancer pain treatment. It is normal to want to be comfortable; it is a way of taking care of yourself.

Many of us are fearful about pain medications because we don't know the facts. It is the responsibility of the health care team to help patients and families understand that while fears about substance misuse, sedation, and other side-effects are common, they are exaggerated. Most side-effects of pain medications are treatable and should never be used as a reason to discontinue treatment for pain.

I have the right to have pain resulting from treatments and procedures prevented, or at least minimized. The treatment of diseases often includes painful tests and procedures. Patients should not be told that pain from treatments is unavoidable, or that it won't last too long. Pain is suffering, no matter how long it lasts. Worrying about future painful treatment is also suffering. The health care team must make sure patients know what to expect when undergoing any procedure and prevent or minimize procedure pain as much as possible.

Adapted and used with permission from “A Bill of Rights for People with Cancer Pain,” Created by Cancer Care Inc. in cooperation with the Iowa and Wisconsin Cancer Pain Initiative

PAIN AND PAIN MANAGEMENT

Recognizing Pain

What is pain?

Hurting or discomfort.

A condition that can cause physical, emotional, spiritual, and financial suffering.

An experience that can only be felt and described by the person with the pain.

BELIEVE THE PATIENT! Pain is whatever the person says it is, occurring whenever and wherever the person says it does. People have different ways of coping. Their pain may not look like you think it “should.” Patients in pain may display any of the following either at rest or while being moved:

Sleeping a lot of the time or having difficulty sleeping.

Distracting from pain by watching TV, humor, conversation, listening to music, and guided imagery.

Describing pain as hurting, aching, specific or generalized (“hurt all over”).

Facial expressions such as grimacing, frowning, looking sad, and wrinkling of the brow.

Moaning, crying out, or groaning.

Difficulty concentrating.

Rubbing or protecting the place that hurts.

Changes in eating patterns.

Changes in usual behaviors (for example a very vocal patient becomes quiet, or a very quiet patient becomes very vocal).

Changes in activity level or resisting activity or movement.

Withdrawal from family, friends.

Report any of the above behaviors to your hospice team.

Recognizing Nonverbal Signs of Pain

Patients may not be able to speak or describe their pain. Their inability to speak does not mean they can’t communicate their pain. Patients may display any of the following behaviors:

- Grimacing, frowning, looking sad, wrinkling the brow.
- Restlessness, fidgeting, rocking back and forth.
- Moving slowly, protecting a body part, or pacing.
- Noisy, labored breathing.
- Looking scared, worried, or troubled.
- Wringing hands or clenching fists.
- Pulling at or touching a body part or area.
- Increased confusion, restlessness, or agitation.

Report any of the above behaviors to your hospice team

Things you can do: Ask the patient if there is pain or if they are hurting anywhere. Patients who are non-verbal or have dementia may be able to answer questions by nodding or with eye movements. Ask family members and other caregivers if they have noticed any changes in behavior that might indicate the patient is having pain.

MANAGING PAIN

What to Report to The Hospice Team?

When a patient indicates that they are in pain gather as much information as you can in order to give the team a complete picture.

- How bad is the pain? On a scale from 0 (no pain) to 10 (worst pain imaginable).
- The location of the pain.
- If the pain affects the patient's usual activities.
- What makes the pain worse?
- What makes the pain better?
- Does the current medication alleviate the pain?
- Are there side effects associated with the medication (constipation, nausea, vomiting, sleepiness, dizziness, itching, etc.)?
- What words best describe the pain (aching, burning, gnawing, stabbing, etc.)?
- How is the pain affecting the patient (disrupting sleep, causing irritability) and family (causing anxiety or worry)?

What Can Be Done?

The hospice care team is focused on comfort care, which includes effective pain management. The team will try to find the source of the pain, discuss options with the medical director and hospice pharmacist, and talk over a treatment plan with the patient and their family. Typically, medication is necessary to relieve severe pain. It is important that the patient takes the medicines as ordered.

- Any medication side effects should be reported to the hospice nurse. The side effects often subside after a few days or can be managed.
- Non-pharmacological approaches can also be tried: Relaxing activities, Distracting activities such as watching TV, listening to music, or playing a game, Heat (a heating pad or warm compress) or cold (an ice pack), Aromatherapy, Distraction or thinking of other things, and Guided meditation

A Word About Words – How We Talk About Opioids

Opioids, often called narcotics, are commonly used in hospice to keep patients comfortable. They are often the most effective treatment for pain or air hunger in hospice patients. Speaking about them matter-of-factly, as one of the tools we use in treatment, can help ease any discomfort or worry that a patient or their family might have.

The recent rise of deaths due to opioid substance use disorders (often due to the unwitting use of very potent drugs that have made their way into the street drug supply) has made patients, their families, and some clinicians wary of narcotics. They are powerful drugs that when misused, can be harmful. When used as prescribed, however, they are an effective and non-addictive method of pain control. At end of life, opioids bring peace and comfort to patients.

The increased publicity of narcotic misuse has also affected how our society thinks and talks about those medications as we begin to understand the phenomenon more completely. Increasingly, substance use disorder (SUD) is being recognized as a chronic, relapsing, and treatable disease. People who live with SUD can, with medical and social care, live healthy and productive lives.

It is important to use person first language, which is non-stigmatizing. Describing someone as “a person with substance use disorder” vs “an addict” puts the person and their disease in the center of the conversation. Words such as “addict” elicit negative associations, punitive attitudes, and emphasize individual blame.

Opioid Myths

Myth: Opioids are addictive.

Reality: There is a difference between physical dependence and substance use disorder (SUD). Physical dependence is a state in which physical withdrawal symptoms occur when a medication is stopped or decreased abruptly. SUD is a chronic, treatable disease of

mental and physical dependence resulting from long-term exposure to substances. Terminally ill patients do not become physically or mentally dependent on opioids and derive great comfort from them.

Myth: Opioids cause respiratory depression.

Reality: When opioids are adjusted slowly to provide pain relief, respiratory depression is rare.

Myth: The patient should avoid large doses as they will render the opioids ineffective drug when the patient's pain management needs increase.

Reality: There is no maximum dosage for opioids. A patient should get whatever dose is needed to provide pain relief. The focus is not on "the numbers" but on controlling pain.

Myth: Giving opioids to a terminally ill patient will hasten death.

Reality: Research shows that the use of opioids does not lead to a quicker death. Being in intense pain, however, might inhibit a patient's ability to "release." If the patient chooses to be treated with opioids, withholding them at end of life is not appropriate. Opioids relieve pain and suffering.

Myth: Opioids cause a person to feel foggy and lose control.

Reality: When opioids are taken on a regular basis, tolerance quickly develops and the feeling of being foggy or out of control typically goes away within a week.

Myth: Opioids damage the body.

Reality: Opioids are very safe drugs when used as directed. Of interest, the American Geriatric Society has determined that opioids are safer for older people than non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or naproxen.

Myth: Using opioids means that you are a weak or bad person.

Reality: Opioid use and misuse in the United States has increased precipitously since the late 1990s when pharmaceutical companies reassured the medical community that patients would not become addicted to opioid pain relievers and gave misleading prescribing guidance to healthcare providers. Increased and incorrect prescription of opioid medications led to widespread misuse of both prescription and non-prescription opioids before it became clear that these medications, contrary to what providers were being told, could indeed be highly addictive. The intense news coverage of the opioid crisis has been frightening and has brought up questions about the use of opioids for pain management. Narcotics are powerful drugs, and their efficacy as a form of treatment has been overshadowed by the unfortunate increase in deaths due to overdoses amongst those suffering from SUD.

Myth: All types of pain respond well to opioids.

Reality: Pain caused by bone or nerve injury (neuropathic) may need the help of additional medications along with opioids to provide better relief for these types of pain.

Non-pharmacologic interventions for pain and symptom management that a volunteer can provide

Physical

Gentle touch, holding hands

Exercise

Massage, energy work, reflexology, craniosacral (if qualified)

Psychosocial

Life Review

Relaxation

Imagery

Distraction

Music
Spiritual
Prayer, if requested
Reflection
Meditation
Life Review
Spiritual Readings, if requested

Barriers To Pain Management: Without even realizing it, we all have attitudes about pain and its management. Our assumptions have been built and reinforced by our culture, our families, and the society in which we live. All of us-- patients, clinicians, and volunteers-- benefit when we strive to understand the underpinnings of our assumptions and recognize that what we consider to be "true" is only one perspective among many.

Barriers Related To Health Care Professionals: Inadequate knowledge of pain management, Poor assessment of pain, Concern about regulation of controlled substances, Fear of patient addiction, Concern about side effects of analgesics and/or Concern about patients becoming tolerant to analgesics.

Barriers Related to Patients:

Reluctance to report pain
Concern about distracting physicians from treatment of underlying disease
Fear that pain means disease is worse
Concern about not being a good patient if they complain of pain
Reluctance to take pain medications
Fear of addiction or of being thought of as an addict
Worries about unmanageable side effects
Concern about becoming tolerant to pain medications such that there will not be anything to take if the pain gets worse.

Barriers Related to the Health Care System:

Low priority given to pain treatment
Inadequate reimbursement in that the most appropriate treatment may not be reimbursed or may be too costly for patients and families
Restrictive regulation of controlled substances
Problems of availability of treatment or access to it

Consequences of Untreated Pain

The consequences of unrelieved pain can be profound; it has an impact on all dimensions of life. Hospice recognizes this, which is why we make pain management a priority in our care. Left untreated or inadequately treated, pain can result in the following related symptoms:

Physical: Fatigue or decrease in activity: Results in diminished strength and endurance.

Poor appetite or anorexia: Results in diminished strength, delayed wound healing, and reduced tolerance of disease and/or treatment.

Nausea: Compounds problem of poor appetite and anorexia.

Altered sleep: Insomnia or fractured sleep due to pain can diminish the patient's overall sense of well-being and affect their coping abilities. Staying on an even keel when you are exhausted is hard!

Altered immune status: The physical and psychological experience of pain can compromise the immune system.

Psychological: Diminished leisure, enjoyment: Being held back from enjoying life due to pain can result in isolation, depression, boredom, and hopelessness.

Anxiety: The fear of pain can keep the patient feeling on edge. The experience of pain is equally psychologically destabilizing.

Depression: Pain often serves as a constant reminder of disease, uncontrollable disease progression and death. It may evoke concerns of diminishing quality of life and loss of control.

Loss of control: Pain may impede everyday functions, normal family activities, and self-care. The patient's self-concept can change as a result. They might feel "useless" due to their restrictions.

Difficulty concentrating: When distracted by pain it is next to impossible to attend to the task at hand.

Not following the plan of care: Patients may become so distressed by pain and treatment induced toxicities that they forgo treatment or seek unproven therapies simply because they will induce little or no pain.

Agitation, irritability, or anger: Pain, anxiety, and loss of control can cause many individuals to feel very angry and frustrated.

Fear: Pain, and the possibility of increased pain, is an extremely frightening experience for patients and their caregivers.

Suicidal ideation: Pain, or fear of pain, may create a sense of hopelessness, and a painful life might not seem worth living.

Social: Diminished social relationships: Pain interferes with the ability to interact with others. Many people become isolated and do not leave their homes when pain is not controlled.

Sexuality or affection: Pain can interfere with an individual's ability to provide or receive physical attention; loved ones may be reluctant for fear of hurting the individual with pain.

Financial effects: Pain may prevent individuals from returning to work which may not only cause a financial burden but can also change their family or social role. In addition, pain medications and therapies may be quite expensive, causing patients to have to choose between therapy and other necessities.

Spiritual: Increased suffering: Suffering denotes an extended sense of threat to self-image and life, a perceived lack of options for coping, a sense of personal loss, and a lack of a basis for hope.

Religiosity: Pain can cause an individual to question their beliefs or feel as though they have somehow displeased their God, for which they are now being punished.

Altered meaning: Pain may create a sense of hopelessness which can result in feeling as though life is not worth living if in pain. Pain may also serve to positively impact one's life and sense of purpose.

Purpose: Culturally, pain may be expected and considered positive or purposeful, helping to heighten an individual's place in an afterlife. This would require a unique approach to pain management.

Dying

WHAT TO EXPECT AS END OF LIFE APPROACHES

The dying process is unique, yet there are common stages that tend to occur when one is within months, weeks, hours, and minutes from death. These stages will vary in order and duration and involve not only physical symptoms but also emotional, spiritual and/or mental signs and symptoms. Understanding these changes demystifies the process; death is not a series of medical emergencies requiring emergent or invasive interventions but a natural way in which the body shuts down.

Sometimes, a patient shows all the signs that death is imminent, but it does not come. It is possible that the patient has work left to do: unresolved conflict, letting go of regret, needing to know that friends and family will be okay, giving or receiving forgiveness. They may be waiting for the final chance to say goodbye, either by phone, letter, or for a certain family member to arrive at their bedside. Equally, they may be waiting for the room to clear of all family and friends. In some cases, for those who appear emotionally, spirituality, mentally at peace death may not come as expected because the physical processes necessary for the body to shut down are not yet complete. This is a time for patience and to honor the body's resilience.

The physical, emotional, spiritual, and mental signs and symptoms are all natural events that may happen as end of life approaches. Not every person will show all these signs and symptoms, and the sequence of events will unfold differently for everyone. Each person is unique; let them be your guide as you carefully and lovingly observe and care for them during their final stages of life.

One To Three Months

SLEEPING MORE: The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive. At times they may be difficult to arouse. This is normal and is due, in part, to changes in the metabolism of the body. What you can do: Sit with your loved one. Gently hold their hand. Identify yourself by name and speak in your normal voice. Do not shake the person in an effort to wake them. Speak to them directly as you normally would, even though there may be no response. Never assume the person cannot hear (hearing appears to be retained until death). Plan to spend time together when they seem most alert.

WITHDRAWING: A normal part of the end-of-life process may include withdrawing from friends, family, and the world around you. The person may lose interest in visiting with people and need time to be quiet or alone. Withdrawing may be necessary as one prepares for detaching from surroundings and relationships. What you can do: Provide opportunities for your loved one to be alone even if for short periods of time (while maintaining their safety). Even if your loved one seems unable to hear you, tell them specifically when you are leaving and when you plan to return. Do not take your loved one's need to be alone personally; your understanding is a gift.

CHANGE IN APPETITE: Your loved one may have a decrease in appetite and thirst, wanting little or no food or fluids. This can be difficult to witness because food nourishes the body and prolongs life. For those with a normal appetite, it is difficult to understand the lack of appetite (not feeling hungry) for someone who is dying. Eventually, too, your loved one may have difficulty swallowing and prefer small chips of ice, frozen popsicles or juice which may be refreshing in the mouth. What you can do: Prepare food based on the person's personal preferences (which may vary from day to day). She may want foods that are soft and/or have more flavors. There may be times when the taste or smell of familiar foods in small amounts is comforting. Do not try to force food or

drink. Do not use “guilt” or persuasion to coax eating or drinking. Consult your hospice nurse, but generally this is not a time to worry about special diets.

FATIGUE/WEAKNESS: For someone approaching end of life, fatigue and/or weakness may be their greatest source of discomfort. Often energy is limited and there is inability to endure lengthy social events or visits. Weakness can create the potential for falling. The person may also become unable to move to a comfortable position in their chair or bed. What you can do: Check to see when assistance is needed. Talk to the person about being safe from falls so that they do not suffer an injury. Understand that weakness and/or fatigue caused by a life-limiting illness tends not to diminish with exercise. Do not “push” the person to exercise to gain strength. If your loved one wants to exercise, help them with limited movements/range of motion. Ask what kind of activities the person wants and for how long.

One To Three Weeks

VISION-LIKE EXPERIENCES: Your loved one may speak to, or claim to have spoken to, person(s) who have already died. They may also see, or claim to have seen, places you cannot see. This is not necessarily indicative of hallucinations or drug reactions because “visioning” is a common experience even for those who do not require medication. What you can do: Do not contradict, explain away, or argue about what the person has seen or heard. The experience is real to them even though you can’t see or hear it. Affirm their experiences by asking about what they saw. Affirm for your loved one that visions are normal and common.

FEVER/CHILLS: As the body becomes weaker, so does the temperature control mechanism in the brain; this can cause the person to have a fever or cause the body to become cool. As the body becomes weaker, circulation decreases so they may feel cool to the touch. What you can do: If a fever develops let your hospice nurse know. Often placing a cool washcloth on the forehead and removing blankets may be all that is needed. The hospice nurse can assess for any needed medications. Consider using a fan or open a window. If the person is cool, keep them warm with a blanket. Electric blankets should not be used. If the person is cool and becomes restless, removing blankets may decrease the restlessness.

DISORIENTATION: Your loved one may seem confused about the time, place and/or identity of people surrounding them (including those with whom they are most familiar). This is due in part to metabolic changes. What can you do: Identify yourself by name rather than asking the person to guess your name. Speak softly, clearly and truthfully when you need to communicate something important related to comfort such as, “It’s time to take your medicine.” In addition, explain the reasons for the communication such as, “So you don’t begin to hurt.”

INCONTINENCE: The person may lose control of bladder and/or bowel function as their muscles begin to relax and they become less aware of their surroundings. What you can do: Discuss with your hospice team what you can do to keep your loved one clean and comfortable including using disposable briefs and/or pads on the bed. Often the care required is too much to manage alone; consider how to incorporate the help of friends and family and/or hire professional caregiving help.

PHYSICAL RESTLESSNESS: Restless and repetitive motions, such as pulling at bed linen or clothing, are common at end of life. This is due, in part, to the decrease in oxygen circulation to the brain and to the body’s metabolic changes. What you can do: Do not try to restrain such motions. Remain calm. Speak in a quiet, natural way. Lightly massage the forehead, read to the person, and/or play soothing music. When in doubt, consult your hospice nurse.

BREATHING PATTERN CHANGES: Your loved one’s regular breathing pattern may vary. One common pattern consists of irregular breaths—shallow breaths then periods of no breathing for 5 to 30 seconds or more; this is called “Cheyne-Stokes” breathing. A person may also experience periods of rapid, shallow, pant-like breathing. These patterns are very common and can be indicative of decreasing circulation in the internal organs. What you can do: Elevating the head of the bed and/or turning the person on their side may bring comfort. Gently hold their hand. Speak gently.

Hours To Days

SURGE OF ENERGY: Your loved one may experience a surge of energy which is short in duration. This may happen for a variety of reasons such as the need to attend an important family gathering or because they are no longer taking certain medications. Sometimes this energy surge gives caregivers/loved ones a false impression that the person is getting better. What you can do:

Enjoy this time for what it is. Reminisce and create new memories as you spend this meaningful time together.

MENTAL/SPIRITUAL RESTLESSNESS: The person may perform repetitive and restless tasks. This may indicate physical discomfort or that something emotional is unresolved or unfinished. What you can do: Consult your hospice team members for help in identifying for your loved one what is physical versus emotional/spiritual/mental discomfort; discuss strategies for resolution. Recall for your loved one a favorite place or experience they enjoyed or that you enjoyed together. Thank them for their presence in your life. Give them examples of how they have made a difference in the world. Read something comforting. Play music they have enjoyed. Offer words of forgiveness related to situations that involved strife. Give assurance that it is OK to “let go” and provide specific examples as to how you will be OK without them.

GIVING PERMISSION/SAYING GOODBYE: One of the most difficult tasks at end of life may be giving permission to “let go.” It can be emotionally painful to picture life without your loved one. It’s normal not to want them to die. Experience tells us, however, that a dying person will try to hold on (even if it means prolonged discomfort) if there is uncertainty for the well-being of those they are leaving. What you can do: Saying “good-bye” is a gift that can help achieve closure for the living and the dying. It’s important to say everything you need to say such as, “I love you” and “Thank you for...” Saying goodbye may include recounting favorite memories, places and activities you shared. It may include saying, “I’m sorry for whatever I contributed to tensions or difficulties in our relationship.” Give examples of specific ways in which you will be OK when they are gone. It’s important to offer reassurance that it’s alright to “let go whenever you are ready.” It may be helpful to lie in bed and hold your loved one. Tears are a normal and natural part of saying “good-bye;” they do not need to be hidden from your loved one or apologized for.

URINE DECREASE: Urine output normally decreases and may become “tea” colored or have an unusual odor. This is referred to as concentrated urine. This is due to the decrease in fluid intake as well as the decrease in circulation through the kidneys. What you can do: Consult your hospice nurse to determine whether there may be a need to insert (or irrigate) a catheter.

CONGESTION: It’s common to hear gurgling sounds coming from the chest or throat. These sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and can cause discomfort. The sound of the congestion does not indicate discomfort. What you can do: Gently turn the person’s head to the side and allow gravity to drain the secretions. You may also gently wipe their mouth with a moist cloth.

MOTTLING/WEAK PULSE: Hands, arms, feet and sometimes legs may become increasingly cool to the touch and at the same time the color of the skin may change. The underside of the body may become darker. The skin may become mottled. These are normal indications that the circulation of blood to the body’s extremities is decreasing and is focused on the vital organs. What you can do: Do not be alarmed and understand that these signs do not indicate discomfort and are not unusual for someone who is within the stages of “actively dying.”

End-Of-Life Nutrition And Hydration

Just as there is a natural yet miraculous process for birth, there is also a natural yet miraculous process in death. The difference is that the details of dying are rarely discussed, yet are a significant part of life. Hospice is founded on the belief that the body adapts as a disease progresses and death approaches. This process should not be interfered with unless it can benefit the patient.

Food is nourishment for the body and soul, and language of love and comfort. During times of great distress, families turn to familiar traditions for providing comfort and expressing love. When someone stops eating and drinking, it is normal to feel helpless; food and water are requirements of good care and love throughout life. Understand that good care can be expressed in ways other than eating and drinking. For the majority of the terminally ill, food and fluids do not increase quality or quantity of life. In fact, when a person is artificially fed and/or hydrated, it usually increases pain and suffering. Allowing someone to accept or refuse food and fluids enhances their control and quality of life. Experience and evidence show that death without artificial nutrition and hydration is a natural process. The body is an amazing machine, even at the end of life. Most dying people feel little hunger. They eat and drink very little or refuse food and fluids. Remind yourself that this is not a healthy person refusing to eat and experiencing hunger pains. Adding food and fluids to a dying body may cause stress.

When disease progresses and death approaches, organs decrease their normal level of functioning. When a person is fed at this point, the body is unable to process food and fluids normally. The outcome may be discomfort and increased suffering, with symptoms such as swelling, bloating, coughing, nausea, vomiting, or difficulty breathing. Keep in mind that feeding through a tube or IV is also giving foods and fluids.

Dehydration is a natural anesthetic. In the dying patient, dehydration provides relief because there is a change in mental status, which can lessen the patient's awareness of suffering. Not eating should be looked on as one of the components of the natural dying process and not the cause. The most negative side effects of dehydration include thirst and dry mouth, which can be alleviated with good mouth care. This is an opportunity for love to be expressed in a new way. The hospice team will teach the family how to provide good mouth care that can bring relief and allow them to have the quality time that they deserve. Always remember to let the patient be the guide to what they need or desire.

Signs And Symptoms Of Approaching Death

what are the signs and symptoms that the patient is close to death?

As death nears, the patient may:

- Sleep more
- Speak to people not present
- Talk about leaving or taking a trip or journey
- Withdraw from people or have little to say
- Eat or drink less
- Have trouble swallowing
- Become more confused
- Make moaning sounds
- Lose control of urination and bowel movements
- Have moist breathing or sound congested
- Have changes in the pattern of breathing such as long periods without breathing followed by several quick, deep breaths
- Have blurred vision
- Not hear as well as usual
- Experience less pain
- Have cool feeling hands and arms or feet and legs
- Turn blue around nose, mouth, fingers, toes

If you observe any of the above, report it to your hospice team.

What can be done? The team will work to relieve symptoms and increase comfort. Comfort for the patient and family is the goal of the hospice team.

Things you can do:

- Allow the patient to sleep as much as they wish
- Turn the patient if it makes her more comfortable
- Moisten the patient's mouth with a moist washcloth or cotton ball
- If the patient has a fever or is hot, apply a cool rag to the forehead



Write down what the patient says. Such messages may be of comfort to the family

Continue to talk clearly to the patient. Remember that the patient may be able to hear even when not able to respond

Keep a light on in the room. The patient cannot see well and may be scared by darkness and shadows

Play the patient's favorite music softly

Talk directly to the patient and tell the patient who you are

Keep things calm around the patient

Open a window or use a fan in the room if the patient is having trouble breathing

Tips For Nearing Death Awareness

What is nearing death awareness?

A special knowledge about the process of dying that some patients experience

The attempt of dying people to describe what they are experiencing

It may be an attempt to request something the person needs for a peaceful death

What are the some signs of nearing death awareness?

Appearance of confusion

Seeing and/or speaking to those already dead or spiritual beings

Talking about seeing other places of light, peace, or beauty

Uses symbolic language – talks of journeys, luggage, standing in line, going home

May begin to ask for people with whom they need closure

What do you need to do?

Report this to the Hospice Team

Listen carefully to the person and affirm their communication

Ask gentle questions if the person is expressing a need

Involve the family in this experience and support them – assure them that this is not confusion but is a significant change in condition

Understanding The Final Messages Of The Dying

Frequently, people who are dying will say things that seem hallucinatory. Listen to these words well. Although they may be jumbled and rambling, these final communications often hold important meaning for those who are leaving this world and for those whom they are leaving behind. Family members, thinking that their loved one's "mind is wandering," that "she doesn't know what's going on anymore," are often more distressed by this behavior than by physical symptoms. Frightened and anguished, they may try to humor or reorient her. Medical staff may give medication to try to "calm" her. But these measures can compound the dying person's sense of isolation and bewilderment. Instead, if we listen carefully and gently, we may be able to understand what the dying are struggling to tell. Sometimes they're telling us what's happening to them in those last hours or weeks. Sometimes they're asking for something that will help them die peacefully. By helping to interpret these hidden messages, we can ease the anxiety of patients and family members and help them find a special closeness. In working with hundreds of dying patients, we've found that they're generally mentally at ease or "busy" in a purposeful way, trying to work out one last thing. And, most important, we've identified several recurring themes.

Being In The Presence Of The Dead

The dying commonly talk to or "see" someone who's died. Here is how a hospice nurse drew out such a patient. Laura, 81, was cared for at home by her husband, Joe. She was particularly concerned about leaving him because he relied heavily on her. A year before,

her daughter Susan had died of cancer. During a visit two weeks before Laura died, the nurse noticed that she seemed distant and withdrawn. Joe and a nursing assistant reported that she rarely talked anymore, always seemed to be “looking through” them.

Wanting Laura to know she would like to share whatever she was feeling and experiencing, the nurse said, “Laura, what’s happening to you? Where ‘are’ you, dear?”

“It’s time,” Laura said, “to get in line.”

“Tell me about the line,” she said, never questioning its existence. “Is there anyone there you know?”

Smiling, she replied, “Susan.”

“How nice for you.” Then, exploring further, “Would you like to get in line? Is it okay? Tell me more.”

The smile vanished. “But Joe,” she said, “can’t go with me.”

“That must be a hard choice for you.” Indeed, it was the heart of her dilemma. “Can we help Joe get ready for the time when you have to get in line.”

“Yes.”

The nurse repeated the exact conversation to Joe. He wept but took comfort in the realization that Laura was looking forward to being with Susan again. And he added another bit of insight. He and Laura had traveled extensively in their lives, and now for this solo voyage, perhaps she was remembering the many times they’d stood in line during their travels together.

It was obvious from the conversation that Laura, like so many dying patients, was caught up in the struggle of whether to stay or go. She needed “permission” to die in peace. And Joe was able to give it, to talk to her about the plans he’d made for his future, to assure her he would be all right. She grew peaceful and remained so until she died.

Preparing to Travel, Change

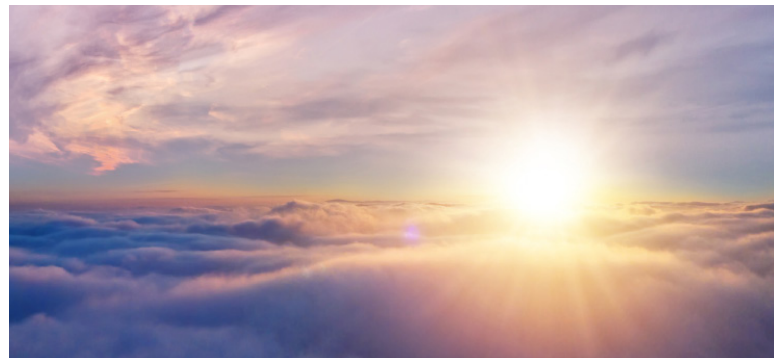
As we saw with Laura, the theme of travel is a familiar one with the dying. John, 20, suddenly began asking, “Where am I? How do I get home? If I could find a map, I could get home.”

His parents attributed his confusion to the fact that they’d moved him from his bedroom on the second floor to a room on the first floor next to theirs. In an attempt to reorient him, they moved in all of his things from his own room and even hung a map of the town on his wall. But his confusion and agitation increased. We suggested to his parents that he might be trying to find his way to his new home. They felt we were right and, fighting their grief, reassured him that he would find his way soon, that they were ready for him to leave them. His anxiety and frustration drained away; he died the next day.

Seeing A Place

Many dying people have glimpses of “another world.” Others speak of having a “dream” or a “feeling of being in another place.” And it doesn’t happen only when death is imminent; it can occur weeks before.

For instance, Bob, 42, spoke coherently only once in the last 24 hours of his life. “I can see the light down the road,” he said, “and it’s beautiful.” Peter, 51, told us 2 weeks before his death, “I can see through the doors to the beautiful scene.” It was 3 weeks before she died that Elizabeth, 60, said, “When I woke up this morning, I thought I had died and an angel was seen in the light coming through the window. I was so disappointed that it was my daughter and that I was still alive.”



This phenomenon can comfort some patients but puzzle others. Thus, one of the nurse's roles is to help them explore what it was like if they want to, and to offer reassurance if necessary. It's important to remember, too, that families often need to be reassured that this isn't caused by drugs or mental dysfunction, that it's indeed common.

Choosing When To Die

Most of us are aware that the dying often seem to cling to life until a loved one arrives. But we also see patients wait until a loved one leaves. Jean, 59, lived with her friend Barbara. Piecing together some things Jean said, a hospice nurse realized that the woman didn't want Barbara to be alone with her when she died. The hospice nurse assured Jean that she would arrange for nurses to be with her 24 hours a day. Jean, who had developed a close relationship with the nurse, said, "I'd prefer if you were with her."

Several days later the hospice nurse visited Jean as she lay dying, apparently comatose. A shift nurse was with her; Barbara was in the next room. Leaning over Jean, the hospice nurse told her she didn't think it would be much longer, that it would be easy from now on, that Jean should go whenever she wanted to.

Kissing Jean's cheek, she said, "I'll be back in a little while. I'm just going to spend some time with Barbara in the other room." Within minutes Jean died, the shift nurse at her side, the hospice nurse with Barbara as Jean had wished and planned for.

Knowing The Image Of Death

Many times, the message the dying give is that they're about to die. Eileen, 19 told it to her father- without really saying it. She called him from the hospital to say, "I love you, Dad. I want to thank you for being such a good father." When he told her he was coming to see her after work, she said, "I need to tell you now. I won't be able to then." Since Eileen was in a stable period and her friends would be visiting that evening, he thought she meant that the two of them wouldn't have a private time together. Eileen was in a coma when he arrived, and she died that night. But she'd said, in her own way, her good-bye.

Confusion Of The Dying

Not only is it essential to listen to the dying with complete attention but also to let them know you're listening. Here are some techniques we've found helpful:

Respond in ways that tell them you accept whatever they say or "see."

Follow up what they say in a gentle way. Ask questions and offer sensitively probing insights that might encourage them to keep talking.

Make them repeat statements if necessary. Don't be afraid to say, "I'm not sure I follow you. Can you explain that a little more?"

Support them. For instance, if they're having difficulty "letting go," don't deny the problem. Acknowledge it and offer to help.

Equally important, however, don't keep pushing. If they don't want to talk, drop it – they have to be ready. But at the same time, reinforce that you're still greatly interested, that they should let you know whenever they want to talk.

The Family

It's often easier for family members to grasp what the patient says, to understand the possible symbolism and references, because of their knowledge of his lifestyle, experiences, values, and usual way of talking. So, you should familiarize them with the key things the dying talk about and impress upon them the importance of listening carefully and trying to come up with meanings. If the family isn't present when the patient talks to you, be sure not only to relay the conversations to them but also to do it as precisely as you can. They, in turn, should report what he says when you're not there. Encourage them to interpret it for you, even if they say it will be just a wild guess. And give them whatever fragments of an interpretation you may have. As you talk it out, it may make more sense than any of you thought. Family members go through so much together in their lives. They share so much with each other. And this too, the time of dying, can often be a wonderful time of sharing – if we but help.

—Maggie Callanan Pflaum, RN, Home Care Nurse, Arlington, VA & Patricia Kelley, RN, Nursing Education

The Volunteer & The Patient

A PRACTICAL GUIDE FOR A RESPECTFUL VISIT

How-To When You Are There With The Patient

In your work as a volunteer, you are entering another person's space. This might be literally – for example as a field volunteer visiting a patient, or a Hospice Care Center volunteer re-stocking a room, or figuratively – as one of our phone volunteers checking in on a patient or caregiver.

Our patients are vulnerable and their space, however they define it, is their last refuge. It is their kingdom. We want your interactions within that space to be successful. You will do well if you remember this central goal: respect the person you are with, in every way that you can. We are all entitled to respect, of course, but being a patient – being treated like a patient rather than a person – can chip away at a person's dignity. Speak with the patient as you would speak to any healthy person. That doesn't mean you might not need to modulate your volume or slow your speech; react to the person in front of you and make appropriate accommodations. It means that you should make every visit assuming competence on the part of the person you are visiting. Keep an open mind and avoid mentally categorizing a person based on how you perceive their physical space, age, gender, ethnicity, or any of the myriad ways we separate each other into groups. Approach the patient without preconceived notions; you will serve them better, and both of your experiences will be greatly enhanced.

When visiting, always knock before entering the patient's space (the ring of the telephone plays the same role for our phone volunteers) and wait for permission to enter. Think how invasive it would feel to have someone enter your space without any warning! You might be nervous, so remember to introduce yourself clearly and slowly, identifying your role and your purpose. For example, "My name is Jane Goodheart. I am a volunteer with EvergreenHealth Hospice, and I am here to visit with you."

Ask the patient and their family members how they would like to be addressed. Often, when one becomes a patient, the family supporters are identified by their roles, not their names. Rather than defaulting to "mom" or "brother," use their preferred name. If the family is not present, keep in mind that in most cases, there is a family, and the patient is not an isolated being. Ask after them.

Even if the patient is expecting you, make sure that this is still a good time for a visit. Who amongst us hasn't made plans only to be too worn out when the day arrives? If the time is not right for the patient, ask if they would like to reschedule and find a mutually agreeable time. If the visit is going to proceed, set an expectation of how long you are going to be there. That way, it is natural for you to leave when the time is up, and it is easy for the family to end the visit. Many patients and their families feel the need to "host" the volunteer or clinicians. Setting a time limit helps take that pressure off.

There are a few ways to make the conversation work. It may seem odd to strategize a conversation but being thoughtful about it ahead of time will take the pressure off when the visit occurs. This can be particularly helpful for telephone visits, where social cues are harder to read and visual cues are nonexistent.

If you are visiting in person, pay attention to your position. DO NOT SIT ON THE PATIENT'S BED! Instead, find a spot facing the patient, and sit level to them. As one of our former nurses said, "putting your heart no higher than the hearts of the people to whom you will listen is respectful. It does not imply a position of power. Thus, the phrase a "heart to heart" conversation."

Of course, "yes" or "no" questions are sometimes appropriate and will be a part of your conversation. In the main, though, try to ask open-ended questions. Some patients, for a variety of reasons, may take extra time to process the question and to respond to it. That pause can feel very long, and sometimes awkward. If you feel that a pause is uncomfortably long, acknowledge it to yourself internally, and then let it go. You will become used to giving time and space with practice, and your conversations, both in your volunteer life and in your everyday life, will become richer for it.

PATIENTS, RELATIONSHIPS, AND BOUNDARIES

"Patients belong to their families, not to us." -Dame Cicely Saunders

YOU AND YOUR PATIENT OR CAREGIVER

Just about every volunteer role has some level of interaction with patients and caregivers. Those interactions might be brief and businesslike, or lengthy and emotionally intimate. Most are somewhere in between, and the nature of those interactions often changes during the patient's stay on our service. A tuck-in caller whose first few calls were focused only on medication needs might one day find the caregiver giving a heartfelt answer to the question "how are YOU?" that results in a 20-minute conversation. A front desk volunteer at the HCC sees many family members come and go; sometimes, the red chair next to the desk is a place of respite, either quiet or full of emotion. Volunteers who visit patients in the field may become very close with both the patient and their family, only to find their role diminishing as the patient approaches their final days. The intensity of end of life, the family's heightened emotions around the patient's transition, and the generous, giving hearts of hospice volunteers make for a situation that requires careful and thoughtful navigation. This is where boundaries come in. Think of them as a tool to protect yourself and to protect your relationships with your patients.

Volunteer's Role And Boundaries

You will never regret a boundary that you set but you will regret one that you didn't. Clear boundaries faithfully kept are crucial to hospice work, whether you are a volunteer or a clinician. Think of boundaries as a property line, defining what your responsibilities are. When you enter a situation knowing what you are allowed and willing to do, you can clearly define that for the person you are helping and avoid confusion or disappointment. Sticking to the boundaries that all hospice volunteers and clinicians are expected to keep makes the work easier for every person who follows you; when you bend the rules, you make it harder for others to stick to them.

Boundaries can be tricky. Our volunteers care deeply about others, and it can be easy to cross a line into an area that is not theirs. Sometimes we want so badly to fix, advise, save, or change that we lose sight of who we are doing that for. Each person has the right to the dignity of their own processes and decisions, regardless of another's opinion. To bear witness to pain requires, as Ram Dass puts it, "infinite unbearable compassion." It also requires the discipline of knowing what is yours and what belongs to the patient and their family. If you move through your work truly knowing that your experiences and emotions are valid, personal, and separate, you will naturally respect that truth for others; the patient, their caregiver, and the rest of the hospice team have feelings about their time with your mutual patient that are equally their own. Sometimes, people will do their best to push back against a boundary. The harder they push, the more you know that boundary was needed. Most boundaries that volunteers need to set are quite simple and can be explained as a matter of policy. Not texting with a family, for example. Yes, it is how many of us communicate and it makes things very simple, but the rules say that volunteers aren't allowed to share their personal information with patients or families. Some requests

to bend the rules seem minor but have long-term repercussions. A field respite volunteer who is asked to extend their scheduled time might say yes because they understand how important that free time is to the caregiver. What was a one-time request could easily morph into a weekly routine. The volunteer may not have or want to give that much time but feels awkward about saying so now that the expectation has changed. On occasion, a volunteer will need to uphold a boundary in a way that is distressing. For example, as volunteers are strictly prohibited from giving patients medication, they could find themselves witnessing great pain which they can't alleviate in the moment.

Thankfully, there is always help in these situations. You are a member of a team! You can call upon the Volunteer Coordinators for advice, or the social worker (social workers are very experienced with the complications and challenges of boundary setting and keeping) for some suggested language or strategies around difficult conversations. The nurses or triage are always only a phone call away for medical concerns. As a hospice volunteer, think of yourself as a "professional friend." It is a useful term that describes your unusual position.

How To Create And Sustain Good Boundaries

Every patient interaction comes with expectations: yours, and those of the patient and their family. Ideally those expectations will be the same, but they may be in conflict. Robust communication about those expectations at the beginning of your relationship will go a long way toward preventing problems. Every volunteer role has a start, which is the best time to define it. A tuck-in caller, for example, begins their very first call by explaining the purpose of their call and their role on the team.

Our HCC front desk volunteers begin their time with our visitors by welcoming them, explaining the need to sign in and out, and if it is their first visit to us, walking them down the hall and orienting them to the building. Respite volunteers in the field set their boundaries with the help of the patient's team, who have already discussed the requested service with the family, and then discuss specifics such as time of day, day of the week, length of the visit, and limitations of the volunteer's role during an initial phone call.

Regardless of position, the Volunteer Coordinators will help you figure out those boundaries, and the patient's social worker is an excellent resource for finding effective language to use.

Why set limits? It will help keep the patient and family from becoming dependent on you. It allows everyone to better understand why you are there and what you are willing to do. It will make it easier to say no, if necessary, or to end your visits when the patient is no longer receiving hospice care.

What are my limits? Think about what you want to do and what you are willing to do. What days of the week are you available? Do you want to do light housekeeping or simply visit? Are you willing to stay on a call once your task is finished to chat with a caregiver? What kinds of tasks do you want to perform to support the HCC staff? Do you want to split your 4 hours of respite time into two different visits? Callers need to be mindful of their intentions before starting a call – a lot of connection over the phone is created by sharing about oneself. Think carefully about your comfort with self-disclosure. Let your volunteer coordinator know your limits. It's okay if your limits change as you have different volunteer experiences. Don't hesitate to turn down a request. Be honest about your feelings and discuss problems as they arise with your volunteer coordinator.

Call Before Your First Visit To Introduce Yourself & Set Ground Rules

Why are you going to be visiting? Explain your understanding of the purpose of your visit: To provide companionship or respite, provide practical help (light housekeeping, laundry, etc.), life review, etc. Find a day and time that you both agree upon. Let the patient or caregiver know how often you will come and for how long. Remember, you may spend up to 4 hours per week with one patient/family—4 hours one day a week, 2 hours two days a week, etc.

Call to confirm before each visit: If your visit is scheduled for the morning, call the afternoon or evening before.

Check in at the nurse's station when you arrive for your shift at the HCC: See what tasks need doing that day, and say yes to the ones you are most interested in. If you have priorities for your work that day, let the team know.

Stay within your limits: Occasionally your limits will be tested. You can change your limits based on a request, but only do so if it truly

something you want to do. As a volunteer, you have the right to show up exactly as you want to, and to do only the work you originally agreed to. It is okay to say “NO.” Healthy boundaries, well considered and faithfully kept, are the most important factor in interacting positively with others. Boundaries don’t distance us from others; they help us see where we end, and another person begins. Boundaries make it safe to be close in a healthy way. Thoughtful boundaries help us clearly state what we need and want in a way that is kind, firm, and respectful. Recognizing what you can comfortably give to another will save you from burnout. Recognizing when you have passed that point will tell you it is time for a break. If you think you might have overstepped your boundaries and, from the desire to help, have diminished a patient or family’s ability to problem solve for themselves, it is time to step back. Allow your patients the dignity of their independence by giving them room to do for themselves. Your boundaries empower the people you are there to help. Take care of yourself – protect your emotional reserves-- so that you have plenty of energy and compassion when you want to take care of others.

SETTING HEALTHY BOUNDARIES

Setting Boundaries

Respect your role and don’t exceed it.

Set limits on your time and tasks.

Don’t set coworkers up for failure by not following common rules.

Do not disclose “secrets” to family.

Avoid conflicts of interest, such as interactions with patients or families that result in monetary gain or bartering goods and services.

DO NOT give medical advice, even if you are sure you know the answer. Don’t give any advice!

Saying “No”:

Decline gifts.

Don’t make promises, despite best intentions.

Be clear when giving a “No” response.

Blame the organization.

Say, “I have to check with my supervisor.”

Dealing With Challenging People: If you find yourself in a situation in which your interactions with the patient or their caregivers feels inauthentic, uncomfortable, or as if you are being manipulated, please reach out to a Volunteer Coordinator or to the patient’s MSW. End of life can be a very stressful and challenging time. People who are feeling cornered or overwhelmed might rely on coping skills that can be negative for those around them. We do not want you to be in danger, be uncomfortable, or find yourself stuck right in the middle of some intensely stressful family dynamics. In those instances, trust your instincts and end the visit.

Some Early Warning Signs That Your Boundaries Might Be Slipping

Here are some “early warning signs” that you might be crossing boundaries:

Giving your phone number or address to patients and families.

Being overly at the ready. Hospice is available 24 hours a day, 7 days a week. You are not and should not be.

Giving your home address to a family. This can put your safety at risk.

Regularly sharing personal or work concerns.

Rearranging schedule to accommodate ongoing changes in theirs.

Thinking that only you can meet their needs.

Considering attending the family's social gatherings.

Wanting to stay connected with family after patient dies.

We all can find bits of truth about ourselves in this list but being aware of these pitfalls is vital to being able to have healthy interactions with patients and families. Talk to your Hospice Social Worker if you have concerns about a situation. We want you to succeed and have a wonderful experience.

Self Disclosure

You will hear a lot about how hospice work is patient focused and “not about you.” In fact, you will hear that so often that you might find yourself confused about how to interact with patients when you finally get to work with them!

Let's break that concept down. What do we really mean when we say that it is not about you? Are you never allowed to disclose anything about yourself? Will your conversations with patients be like those you have with your friends? How do you interact with another person if you are feeling as if you don't have a voice? We do expect you, in your volunteer work, to listen more than you talk. We expect that you will be an empathetic ear for those facing end life and end of life care. Naturally, this can be a very introspective time, and it is appropriate for our patients to share a lot about themselves and their lives, if they choose. You, as the conversational partner, can indicate understanding, offer empathy, and ask questions. Those interactions can and will be informed by your own experiences, but those are not observations you need to verbalize to the patient. Think of the patient as the center of a ripple in the water. Their experiences, thoughts, and feelings ripple out. Adding your perspectives to those ripples dissipates them and changes their course.

Does that mean you can never answer any questions about yourself, or talk about everyday topics like travel, or movies you have enjoyed? Of course not! Light topics of conversation are appropriate if they are patient led. Bear in mind that, in the moment, you might be comfortable with a level of self-disclosure that you could come to regret; it is always best to keep your participation in some topics neutral – work, family, religion, and politics, for example – and to turn the conversation back to the patient or caregiver. Have some general small talk questions in your back pocket for those times.

NEVER give your telephone number, address, email address, social media usernames or other similarly personal or identifying information to a caregiver or patient. As a trusted team member, you might wind up being the patient's or family's de facto 9-1-1 service. At 3 AM. Use Call Blocking or enter *67 before the number you are calling. This will block your number from showing up on patients/families' caller ID for that specific call. (If blocked calls are not accepted, you can call hospice at 425.899.1070 and ask to be transferred.)

Gifts And Invitations

Often, patients and their caregivers feel a need to give back to the team that is giving so much to them. They value the work being done on the patient's behalf and want to show their appreciation by sharing something of personal or material value with the volunteer. This can be a very sticky situation, and a socially awkward boundary to keep.

The issue of gifts – giving and receiving – illustrates the unique in-between position of volunteers. You are not paid staff, but working; not the patient's friend, but important in their personal life. It is not unusual for patients to express their gratitude by offering gifts found in their homes, particularly as they are not able to take trips to the store. In some cultures, there is no gift more prized than one with personal meaning. Those gifts do not cost the patient anything but are highly valued by them. Refusing those offerings can feel very uncomfortable. Accepting them, however, can put the volunteer in a very sticky situation.

Imagine your patient has mild dementia, and in the moment doesn't quite understand what they are giving you. Then, in a more lucid moment, the patient is alarmed when they realize the object is missing. They might believe that a member of the team has stolen it. Equally distressing, unbeknownst to the volunteer, there could be some fraught family dynamics around the object the patient chooses to give to the volunteer. A gift innocently given and received might open some very deep family wounds. Being in the middle of such a situation is not only distressing, it also completely undercuts your role as a friendly and helpful volunteer.

As a matter of policy, EvergreenHealth Hospice Volunteers are not allowed to accept gifts of value over \$10 unless they are shareable (a box of chocolates, or a bouquet of flowers, for example). You can blame this policy if a patient or their family tries to give you a gift of greater value.

In the case of a gift that has no agreed upon value other than the sentimental, we suggest that you redirect the offering while at the same time honoring its intent. Instead of outright refusing the gift, say something like “That painting is so beautiful. I can’t possibly imagine it anywhere but in this room, and I always look forward to seeing it when I’m here” or “You are so kind to offer that vase. I will make sure to bring some flowers to put in it when I visit you next week” or “As this is your favorite book, let’s keep it by your bedside and I can read it to you.” If the patient is not budging after a tactful response, blame EvergreenHealth policy. Please be mindful of bringing small gifts to your patients, as well. A flower picked from your own garden might be a welcome gesture, but anything more elaborate can be awkward for your patient. A recent example is that of a volunteer who knew her patient liked to drink lattes and would bring her one every week. As the gesture was of a nominal cost, prepared by professionals, and something the patient enjoyed, the volunteer thought nothing of it. The patient, however, felt terrible that they were not able to reciprocate, and felt like an inadequate host in their own home. If you are given a gift card by a family, the Volunteer Coordinators will make sure it goes to the EvergreenHealth Foundation on your behalf.

Friends, Clients, Family Member On EvergreenHealth Hospice

You might find yourself in the difficult situation of having a friend, acquaintance, or colleague on our service. In those cases, we ask that you support them as a friend, and not as a volunteer. In your friend relationship, you are free from the policies and regulations that bind your work as a hospice volunteer. Your ability to support them and their family will be far more flexible than it would be as an official volunteer. If you are a volunteer for another organization and you are serving the patient through that service, we ask that you choose one or the other. The patient and family must be clear about which organization you are working for when you are donating your time to them. Should you have a family member being served by hospice – EvergreenHealth Hospice or elsewhere – please consider stepping away from your volunteer work so that you may be fully present for them. Taking care of yourself and your family is a boundary you will not regret setting!

It is possible that you will recognize a friend or acquaintance from a volunteer request or, if you work at the Hospice Care Center, a census sheet. Unless you have been informed by the patient or family of their admission to our service, you may not acknowledge that they are a patient (this includes popping into their room at the HCC to say hello). Telling others – even your close family – is a violation of HIPAA. We understand how difficult this situation can be. The Volunteer Coordinators are always available to offer guidance on how to navigate the complicated feelings that can arise.

Patient Care And Family Concerns

Every family takes care of their patient in a unique way that reflects their values, culture, interpersonal roles, and abilities. It is, of course, our hope that every patient receives care that is gentle and loving. Unfortunately, volunteers might observe care that is not aligned with that hope.

Volunteers have deep concern for their patients and want what is best for them. In your capacity as a volunteer, even if you have a clinical background, you are not a professional or personal caregiver. If you witness care that you believe to be substandard, abusive, or dangerous in any way, please report it to the Volunteer Coordinators and the patient’s team immediately. As difficult as it may be, **DO NOT INTERVENE.**

THE END OF THE RELATIONSHIP

Our relationship with our patients ends in one of three ways: death, discharge, or revocation. It can be very difficult for the volunteer to feel a sense of closure in each of these situations. It is essential, however, that you honor your feelings and the work you did with the family.

Death

This is what we expect when we sign on to be hospice volunteers. We know that in time – days, weeks, or months – the patient will no longer inhabit a physical body. Volunteers are permitted to attend memorials and funeral services if they are invited. We ask that you not attend the reception, however, as that is social time reserved for family and friends. You may also make one condolence call or visit. After that, your relationship with the family is over.

Concluding your relationship with the family can be quite hard; officially ending a friendship is not something many of us typically do. Even if you consider it a professional friendship, you may have come to care for the family quite deeply and worry about how the survivors will manage in the coming months. Remember that hospice is team driven, and the family will have significant support from our Bereavement Coordinators and bereavement volunteers. The bereavement team is also available for you if you are struggling with a particular hospice loss or losses.

If the death of a patient is particularly difficult for you, please consider taking a break from volunteering. The time you spend healing and processing – be it a week or a month or even longer – will prepare you to continue supporting more patients. If you would like to stay connected with your volunteer work in a non-patient-facing role for a while, please contact the Volunteer Coordinators. We will find a different way for you to contribute.

Although it's intended to be supportive, keeping in touch with families after a loved one has died is not helpful to them. Your relationship is based on the memory of that loved one and your ongoing presence could hinder their healing. As a volunteer, you can honor the relationship you had with the patient and family at the end of life by taking what you learned to support your next patient.

If you find yourself unable to let go of thoughts of the patient or family, or if you feel “stuck” in your grief, please reach out to the Volunteer Coordinators or Bereavement Coordinators for help.

Discharge

Sometimes we refer to discharge as “graduation” or “decertification.” Hospice is for patients with six months or less to live, and who are showing evidence of decline. On occasion, when patients are admitted to our service their condition stabilizes or even improves. The clinicians caring for the patient and the medical director may come to believe that the patient will in fact be alive in six months. At IDT, the team assesses a patient's overall condition every two weeks. In addition, at specific intervals, patients must be recertified to continue to receive hospice services.

If the patient hasn't shown evidence of decline, and the team agrees that decertification is appropriate, they begin a conversation about discharge with the patient and family. If one of your patients seems stable or is improving, please check in with the team. You may have to prepare yourself for their possible discharge.

Having one's patient discharged can be a very challenging situation for a volunteer. Your companionship and the service you provided must come to an end, even though they are still of great value to the patient and fulfilling for you. You might have become quite friendly with the patient and their caregivers, and it can be heartbreaking for that friendship to end without the finality of death.

We encourage you to reach out to a Volunteer Coordinator, or to seek support at a volunteer meeting. Many of your fellow volunteers have experienced that unique type of loss and you will benefit from their wisdom, experience, and empathy.

If your relationship with that patient was so important that you struggle with stepping back from it, it is time to think deeply about your role as a hospice volunteer. Loss is a constant in hospice, and there might be times in your volunteer career when you need to take time off or switch roles if you are not able to accept that unhappy fact.

Revocation

Revocation is when the patient or their DPOA decides to end hospice support. This can happen for a variety of reasons: pursuing treatment, moving to a hospice system closer to their family, wishing to be cared for by a different hospice, or being admitted to the hospital (patients and caregivers sometimes revert to routines and call 911 instead of reaching out to their hospice team).

Revocation can be permanent or extremely temporary. Regardless of the reason, once a patient is off hospice, your role is over. If they come back, you can be their volunteer again if that is something you both want.



Diversity and Culture in End-Of-Life Care

HOW TO SERVE PEOPLE WHO MOVE THROUGH THE WORLD DIFFERENTLY THAN YOU.

“Everyone smiles in the same language.” — Unknown

Diversity is having a seat at the table, inclusion is having a voice, and belonging is having that voice be heard.

Cultural Humility: The National Institutes of Health (NIH) defines cultural Humility as “a lifelong process of self-reflection and self-critique whereby the individual not only learns about another’s culture, but one starts with an examination of their own beliefs and cultural identities.”

When We Talk About Diversity And End-Of-Life Care, What Do We Mean?

We mean living the values upon which hospice care is built: encouraging, promoting, and respecting individual self-determination.

Until quite recently, there was an agreed upon overriding culture in the United States, reflective of those who traditionally held power and promoted by the structures of that power (economy, government, media). Smaller, less recognized, and less powerful cultures were defined by their “otherness” from the dominant culture, instead of by their unique characteristics.

In many parts of the world, things are changing quickly and in ways that may feel quite radical to some. EvergreenHealth is entirely in support of any change that brings equity, diversity, and inclusion to all.

The speed and intensity of this change, however welcome, can feel overwhelming and difficult to navigate. EvergreenHealth takes a thoughtful and open-minded approach guided by respectfully listening to employees and incorporating community feedback. There can be no meaningful change without such an approach; it allows room for mistakes to be made and welcomes the chance to think and talk deeply about how to rectify mistakes in a profound and lasting way.

What that means for our volunteers (and staff) is that you are on exactly the right track: throughout your hospice training you are already learning to keep an open mind and to meet people where they are vs. where you expect them to be. Your experiences as a volunteer will provide you with ample opportunities to practice those skills.

Diversity means that no one group defines the culture. While we are more familiar with the inner workings and values of the intersecting groups to which we belong, we can’t assume that anyone we meet adheres to those ways of being. It is imperative to be inquisitive, listen more than we talk, and learn from the experts – namely the people who are sharing their lived experience with us.

There are many types of diversity, all of which can come into play over the course of one’s time as a hospice volunteer: cultural affiliation, sexual orientation, economic status, physical and intellectual ability, health status, gender identity, age, economic status, housing status, race, family structure, level of education, to name but a few.

The one culture that every volunteer and clinician will run into is that of the dying patient. Facing the end of life as a patient is

paradoxically a universal event that can only truly be known through experience. The rest of us can learn about the physical, sociological, emotional, and psychological effects of dying, but as with most cultures, until it is truly our own, we understand it only at a remove. Listen to your patients. They are your best teachers about end of life.

DIVERSITY IN THE HOSPICE SETTING

Our differences are our gifts and help make us a stronger organization.

The Hospice Philosophy Exemplifies, Reinforces, And Teaches Respect For Diversity

We meet the patient/family where they are

We respect and acknowledge those things which make that person who he/she is

We never judge behaviors, attitudes, decisions, or abilities

We acknowledge the complexity of people and respectfully describe them and their situations

We do not use terms that are judgmental: “dysfunctional,” “inadequate,” “substance abuse,” “non-compliant”

We do use terms that are accepting: “don’t know,” “tell me about,” “working toward” “substance use disorder” “patient’s plan of care”

We respect that each patient and their family have different needs, expectations, and desires; there is no such thing as a typical hospice patient

We believe that hospice care is a right, not a privilege

Interdisciplinary Teams As An Example Of Diversity

IDT encourages people from different backgrounds, with diverse experiences, training, and goals to work together to achieve a common purpose. Team members and those they serve benefit from sharing varying perspectives, ideas, and approaches. All team members are teachers and students at different times. We learn from everyone on the team – professionals, volunteers, and especially our patients and families.

Remember: Some of our patients and families will share opinions with us that may not be in alignment with EvergreenHealth’s views regarding diversity. We aren’t here to fix them or teach them. We can, however, learn from our instinctive responses to their perspectives.

Interdisciplinary and cross-cultural work are gifts! Value the diversity represented by your team members, patients, and their families.

Be aware of your own cultural expectations. One’s “home culture” is deeply ingrained, and as integrated into our ways of being as the air we breathe. Experiences and memories from our past provide a specific perspective on our own culture, and may highlight blind spots around someone else’s culture.

The work of truly honoring other cultures and experiences is ongoing and requires robust communication. Understanding, questioning, and listening are all learning; respectfully express your feelings and ideas about diversity with the team.

Any team member subjected to language or behavior they consider to be dangerous, offensive, or inappropriate should report it to their manager.

If you are uncomfortable working with a patient or their family, discuss it with the Volunteer Coordinators.

Cultural Considerations In The Hospice Setting: When we talk about culture, what do we mean? Basically, the word culture describes the ways that a group organizes itself. What can be described as a culture is made up of social institutions, customs, artistic expression, recognized achievements, and celebrated people of any group.

We all belong to a variety of cultures, some that a majority of us share (as residents of the United States, for example), some that are unique to our smaller groups (each individual family, for example, recognizes and celebrates milestones that are important to its members), some we are required to understand (our workplace), and some that we choose to experience intermittently (being a hospice volunteer, part of an extracurricular activity, club, or friend group). As a volunteer, you will experience some measure of a culture that is not your own in every interaction-- even when placed with a patient or interacting with a family who share many of your experiences and values, and whose cultural background is very similar to your own. Similar, of course, is not identical.

On many other occasions, you will be working with patients, families, and facilities whose understanding of the world and how to move through it is very different than your own – possibly in complete opposition to anything you have experienced.

Developing Cultural Competence

Understanding your own cultural and personal beliefs is essential to understanding that your patient holds their own views as deeply as you hold yours. Think about how your culture and upbringing affect your beliefs. You may have certain ideas about:

What causes an illness

What families should or shouldn't do

How to show politeness when talking with someone

Appropriate communication styles

Acceptable ways to show pain

When or how often to seek medical care

The “perfect” death

Remember that your views are just that – your views. Never assume that another person looks at life the same way as you. Consider yourself a learner, and work to value and respect the differences you encounter. Ask questions and be observant! This will help you to:

Avoid cultural stereotypes and misunderstandings.

Learn about accepted ways to show respect. How does the patient prefer to be addressed? Are there certain family members who should be addressed first?

Understand the role that others play in the patient's care: family members, community members or groups, healers, or spiritual leaders may each play a unique role.

Recognize communication styles. Look for clues such as whether the patient makes or avoids eye contact or if the family prefers physical distance or proximity.

Be aware of privacy needs. Is the patient comfortable being touched or unclothed? Are there certain garments that they need to keep on or with them?

Be thoughtful about other factors that may affect care:

Age: An older person may assume that certain problems are part of aging and not mention them, while a younger adult might be worried about privacy and appearance.

Gender: Some cultures prohibit care by someone of the opposite sex.

Sexual orientation: Do not assume that the patient's sexual orientation is heterosexual. In fact, make no assumptions about the patient's sexual orientation.

Views on death: In some cultures, certain actions must happen before or after death.

Socio-Economic status: Financial hardship may affect the choices the patient or family makes. Financial stability may mask complicated family dynamics.

Physical or intellectual limitations: Patients may have differing views of how disabling a certain condition is. Patients may have different mobility or communication needs. Be mindful of neurodiversity and invisible disabilities.

Grief

Grief is like a leaky faucet. Just when you think it's fixed, it comes back again, more bothersome than ever. Perhaps we should not expect an end to the dripping of the faucet, or of our tears: there will always be more where they come from. Instead, we can accept the comfort of a rhythmic letting go, knowing each droplet of grief has the potential to cleanse, to soothe, indeed, to nourish new life.
—Molly Fumia, *Safe Passages*

MYTHS ABOUT GRIEF

Myth: We only grieve deaths.

Reality: We grieve all losses.

Myth: Only family members grieve.

Reality: All those who are attached grieve.

Myth: Grief is an emotional reaction.

Reality: Grief is manifested in many ways.

Myth: Individuals should leave grieving at home.

Reality: We cannot control where we grieve.

Myth: We slowly and predictably recover from grief.

Reality: Grief is an uneven process, a roller coaster with no timeline.

Myth: Grieving means letting go of the person who has died.

Reality: We never fully detach.

Myth: Grief finally ends.

Reality: Over time most people learn to live with loss.

Myth: Grievers are best left alone.

Reality: Grievers need opportunities to share their memories and grief, and to receive support.

DEFINITIONS OF LOSS AND GRIEF

Loss

Traditionally, loss and grief are associated with death. In fact, loss is a much broader concept. We all experience loss constantly; every change involves loss. When we are deprived of, or cease to have something – an attachment, an identity, a physical object to which we have attached importance – we experience loss. The sting of the loss will vary in intensity and scope and the social support around the loss will vary based on how that loss is defined and recognized one's culture.

Physical Loss: The loss of something tangible that is no longer present.

Relational Loss: Losing a relationship with someone to whom one has an attachment.

Symbolic Loss: The loss of a psychological or spiritual attachment, for example loss of one's dreams, hopes, or faith.

Secondary Loss: Losses that result from a primary loss. Losing a job, for example, often means the loss of identity, self-worth, work friends, income, and future plans. Loss Encompasses Far More Than Death. Grief is the response to loss. It lives in the place between our deep desire to have things be the way that they were, and the need to slowly incorporate the fact that our reality has changed profoundly. Grief lives in the tension between the world that was, what it cannot be, and what it might become.

Grief Work: Working through grief is about adapting to the loss, and eventually finding the new normal. Adaptation, also known as coping, is the process of adjusting to the loss, both internally and externally. This is the work of a lifetime. Grief will not end for a bereaved, but instead evolve and change, for it is a continued relationship with the person one has loved and lost.

ANTICIPATORY GRIEF

Anticipatory grief can be experienced by anyone – the patient, family, friends, and colleagues – who is experiencing the loss of a relationship due to terminal illness. Anticipatory grief is not only about the expectation of death, but also grief for the losses that illness brings – loss of physical ability, identity, income, relationships, connection to the broader world. People mistakenly have thought that anticipatory grief is anxiety over watching a loved one die or a rehearsal of the grief that they will feel later. Anticipatory grief is not just post death grief pushed ahead in time or a device for completing the tasks of grief prior to the death. It is a form of grieving losses that are happening right now but in the context of “the space before death.”

The symptoms of anticipatory grief are exactly as other grief reactions. Not everyone is going to have all the symptoms, or the same symptoms as the others around them. Some examples of common grief reaction are:

Emotional: Sadness, anger, fear, guilt irritability.

Physical: Tightness in chest and throat, dry mouth, over-sensitivity to noise, dizziness, fatigue.

Behavioral: Changes in appetite and sleep, clumsiness, sighing.

Social: Desire for support from friends/withdrawal from friends, role changes.

Spiritual: Searching for meaning, questioning values and priorities.

Cognitive: Preoccupation, confusion, inability to concentrate.

There are things the volunteer can do to serve patients and families experiencing anticipatory grief. At all times, remember that grief is a necessary and natural reaction. You cannot and should not take it away or encourage behaviors that mask or deny the existence of grief. You can:

Acknowledge the symptoms as being grief-related (“It sounds like you are grieving not being able to dance with your husband at the Thursday night dance club.”)

Normalize the experience (“I think most people would be tired with all the changes you’ve been through lately.”)

Encourage people to eat, sleep, breathe.

Have people listen to their bodies and take care of themselves...cry, sleep, talk when they need to do so.

Encourage people to let others know what they need (“You just told me that you wish your son visited more; I hope you will tell him that you need that.”)

Support their being gentle with themselves (“This is a hard time. It is understandable that you may not accomplish everything as fast or as easily as you once did.”)

Sadly, anticipatory grief does not appear to have any particularly beneficial effects. The grief after death is not made easier by grieving the many losses before the actual death. Anticipatory grief is also not an accurate predictor of how a person will grieve post death. It is very common to have family members say something along the lines of “I thought I knew what it would be like when she died, but it was completely different than I anticipated.”

Again, anticipatory grief is real, but it is not just worrying about the death. It is a reaction to the losses leading up to death.

-- JeanAnn O'Brien, Former EvergreenHealth Hospice Bereavement Coordinator

Disenfranchised Grief

Disenfranchised grief happened when a loss is not openly acknowledged, socially sanctioned, or publicly shared. In other words, a loss for which the bereaved does not receive – or feel entitled to – support. Often, this is the result of stigma around the cause of death

GRIEVING STYLES

Everyone experiences, expresses, and adapts to grief uniquely. There are, however, typical patterns of grief that have been identified. The two main grieving styles are:

Intuitive Griever: Intuitive grievers are led by their feelings and emotions and will experience and express it in that way. They are more likely to experience their grief in waves of and seek the support of others to help them manage those feelings.

Instrumental Griever: Instrumental grievers are likely to process their feelings and emotions by seeking to understand, and by doing. They are less likely to overtly show their feelings and tend to be physically restless. Their grief, because it is kept closer to the vest, can be misunderstood as being less intense, or as a lack of attachment to the person they are grieving.

WHAT TO EXPECT FROM GRIEF

Feelings

Shock, numbness, sense of unreality, anger, irritability, guilt, self-reproach, sadness, depression, anxiety, fear, hysteria, helplessness, vulnerability, loneliness, relief, mood swings, feelings of being crazy. Physical Sensations: Tightness in the chest and throat, dry mouth, over-sensitivity to noise, dizziness, headaches, shortness of breath, weakness, lack of energy, fatigue, upset stomach, heart pounding, heavy or empty feeling in body and limbs, hot or cold flashes.

Behaviors

Appetite and sleep changes, absent-minded behavior, social withdrawal, avoiding reminders of loss, dreams of loss, calling out to the deceased, restlessness, sighing, crying, increased sensitivity in social situations, experiencing symptoms of the loved one's illness. Social Changes: Desire for support from friends, withdrawal from friends, increased dependency on friends, pulling away from friends, self-absorption (no energy for others), marital difficulties, role changes, increased sensitivity to topics of loss (airplane crashes, accidents, etc).

Spiritual Needs

Searching for meaning, express and review personal view of life (look at personal philosophy of life), question priorities, question values, make connections with friends and family and community, reconcile the presence of sorrow in life. Thought Patterns: Disbelief, sense of unreality, preoccupation, confusion, inability to concentrate, problems with decision-making, thoughts of self-destruction, seeing or hearing or feeling the presence of the deceased.

DAILY SURVIVAL KIT FOR SERIOUS ILLNESS AND GRIEF

You don't have to agree with all of this all of the time. Part of the help is in the doing, regardless of your attitude or emotions on that day. On some levels the help is gradual and often not evident.

Today I am going to try to live through this day only, and not dwell-on or attempt to solve all my problems at once. I can do something for several hours that would be difficult to even think about continuing for several months.

Just for today, I am willing to accept the possibility that there is a purpose to my grieving; that it can be a source of meaning and growth for myself and others, though I may not recognize the ways. And it seems possible that this grief will not be in vain.

Just for today, let me remind myself that I am basically a worthwhile person, worth loving, despite my faults and limits. I deserve the efforts of others to help me through my grief.

Just for today, I want to be aware that it is all right to want too much from people. Grieving brings out and intensifies the small child in all of us. And if I feel hurt when people cannot be there for me, let me remember that they have needs, frailties, and limitations of their own. A lack of response does not mean that they are personally rejecting me.

Today I may feel the need to complain a great deal; I may have little tolerance; I may cry; I may scream. That does not mean that I am less courageous or strong. All are ways of expressing anger over this mess, of rightly mourning my losses. Endurance itself is courage.

It is my life at stake now. So maybe today I can allow myself to be a little less concerned about the reactions or impressions of others. Maybe I can allow myself to feel a little less guilty or bad about what I did not accomplish or give. Perhaps today I can be a little gentler toward myself.

Surviving grief is difficult. At times it seems impossible. But today I believe I can deal with grief. Sorrow runs very deep, but I think I can rise again.

Just for today, I can give grief "the benefit of the doubt." If I am patient and kind to myself, perhaps I will have the energy to do the hard work of grieving and thereby benefit from its lessons.

Just for today, perhaps I can take heart that we are all connected. Even now my endurance (however imperfect) is a gift, an inspiration for others in their difficult grief work.

It seems reasonable that there is a season for everything, and a time for every purpose. Sorrow, loss, and grief have exhausted me and distorted my senses and spirit. Today, however, I can at least find some hope in nature's way. It seems possible to hope that this grief will ease, that a season of balance will return.

Thomas McDermitt (long time cancer patient and skeptic)
The Tom McDermitt Fund
Cancer Support Community, Greater Philadelphia

Things We Say And Do To Avoid Grief

Suppress: Don't talk about it and it will go away.

Minimize: Oh well, older people die.

Physical complaints: Turn grief into exhaustion, headaches, stomachaches.

Work: The coping skill our employers are counting on.

Shop: The coping skill our economy is counting on.

Eat: Comfort foods.

Alcohol and drugs: Just one more drink to unwind.

Travel: Grief won't follow me.

Religion: It's all a divine plan, I must accept it.

Rage/Blame: Those others are at fault.

Displace: Cry over spilt milk instead of what really hurts.

Inquire: Gather information about what you should do and then think you have done it.

Impulsive Behavior: Do anything to move away from the hurt.

Isolate: Crawl into your cave and refuse to come out.

Identification of Grief Avoidance Response Patterns, Alan Wolfelt 1993

The Volunteer's Grief

The Volunteer's Loss Is Similar To The Bereaved's Loss: Working with the bereaved may make us aware, sometimes painfully so, of our own losses. This is particularly true if the loss experienced by the bereaved is similar to losses that we have sustained in our own lives. If a volunteer's loss has not been adequately resolved it might impede their ability to provide meaningful and helpful intervention. A loss that has been adequately integrated, however, gives the volunteer a deeply empathetic base to draw upon when working with the bereaved.

The Volunteer's Fears For Their Own Future Losses: A volunteer's own feared or anticipated losses – their abstract anticipatory grief – may affect their work with the bereaved. While having sustained various losses in the past can help the volunteer to understand what the bereaved is experiencing, it can also mean approaching the supportive role of volunteer encumbered by the knowledge of what moving through grief is really like. The volunteer might worry about experiencing that grief again. Typically, worry about the loss of our parents, children, and partners is at a low level; working with the grieving, and supporting those living through our own worst fears can mean that those fears loom larger than normal. If you find that apprehension getting in the way of being able to do your work, please reach out to a Bereavement Coordinator for support.

The Volunteer's Awareness Of Their Own Dying And Death: A third area in which bereavement volunteering presents a challenge is by making us aware of our own inevitable death. When talking with the bereaved we are put in touch with the inevitability of death and with the extent to which we are comfortable or uncomfortable with dying and death.

Grief Is A Lazy Susan

Grief, I read somewhere once, is a lazy Susan. One day it is heavy and underwater, and the next day it spins and stops at loud and rageful, and the next day at wounded keening, and the next day numbness, silence. I was hoarse for the first six weeks after Pammy died from shouting in the car and crying, and I had blisters on the palm of one hand from hitting the bed with my tennis racket, bellowing in pain and anger. I am no longer convinced that you're supposed to get over the death of certain people, but little by little, pale and swollen around the eyes, I began to feel a sense of reception that I was beginning to receive the fact of Pammy's death, the finality. I let it enter me. I was terribly erratic: feeling so holy and serene some moments that I was sure I was going to end up dating the Dalai Lama. Then the grief and craziness would hit again and I bore it, like a nicotine craving, I would discover that it hadn't washed me away. After a while it was like an inside shower, washing off some of the rust and calcification in my pipes. It was like giving a dry garden a good watering. Don't get me wrong: grief sucks; it really does. Unfortunately, though, avoiding it robs us of life, of the now, of a sense of living spirit. Mostly I have tried to avoid it by staying very busy, working too hard, trying to achieve as much as possible. You can often avoid the pain by trying to fix other people; shopping helps in a pinch, as does romantic obsession. Martyrdom can't be beat. While too much exercise works for many people, it doesn't for me, but I have found that a stack of magazines can be numbing and even mood altering. But the bad news is that whatever you use to keep the pain at bay robs you of the flecks and nuggets of gold that feeling grief will give you. A fixation can keep you nicely defined and give you the illusion that your life has not fallen apart. But since your life may indeed have fallen apart, the illusion won't hold up forever, and if you are lucky and brave, you will be willing to bear disillusion. You begin to cry and writhe and yell and then to keep on crying; and then, finally, grief ends up giving you the two best things: softness and illumination. —“Traveling Mercies” by Anne Lamott

Self-Care

Working with the dying can be emotionally and physically draining. While this is not always the case, it is important to recognize and remember the role of self-care in our ability to effectively do this work. Recognizing when you have reached your limit is important, but so is preventing reaching that limit, and allowing yourself to rest and repair when you have. Although this “Caregiver’s Self-Care Manifesto” is geared more toward full time caregivers than to volunteers, it is full of sound advice that we can all use in our daily lives!

Caregiver’s Self-Care Manifesto

As a caregiver, I cannot avoid getting emotionally involved, nor would I want to.

Empathy allows me to be a good companion. However, I must remember I am responsible to others not for others.

I must work to achieve practical goals for how I spend my time and to achieve a clear sense of expectations and realistic deadlines.

I must learn to listen to my inner voice when it says stop or tells me that I am over involved or out of balance.

My work does not define me.

I am not the only one who can help people.

My family, my friends, my other interests deserve my time and attention.

I deserve to lead a joyful, whole life.

Caregiver, Caring For Yourself Is No Option

Learn to love yourself at least as well as you love the one you are caring for.

Take a little time for yourself each day and a big hunk of time at least once a week.

Give yourself some real relaxing moments through meditation, relaxation techniques, massage, beautiful music, etc.

Learn stress-reducing techniques and use them.

Recognize your own self-worth.

Recognize your own needs and limitations. This may mean having to say “NO” at times.

Do not feel the need to be responsible for everyone else’s happiness and well-being.

Learn to conserve your vital energy.

Pamper yourself occasionally, especially on bad days.

Be patient and considerate with yourself; you don’t realize the stress you are under.

Nurture your spiritual side; pursue things that are uplifting to you.

Eat right, exercise, and get plenty of rest.

Practice the good advice you give to those you love.

Develop the part of you that wants to laugh; seek out the humor in life and, above all, take yourself lightly.

Pay attention to what your body is telling you. Is it tired, stressed, tense?

Create a private life for yourself apart from your caregiving.

Develop a strong support network for yourself. Allow others to help you. It is okay to accept help.

Give yourself a break in more ways than one.

Don't have unrealistic expectations of yourself.

Don't hesitate to reach out for help either from a friend or a professional.

Caring for yourself is not being selfish. You can't care for others if you have not cared for yourself.

Remembering Our Hospice Families And The Care We Provided Them

Some volunteers choose to honor the patients and families they worked with, and to memorialize the time spent in their presence. Here are some suggestions.

Buy fresh flowers the day you hear that your hospice client died. For each flower you put into the vase say aloud a quality or personality trait of the client.

Find a song that speaks to you about death and life. When a client dies, find time to be alone and play that song as loud or as quiet as you like. When the song ends sit for a few minutes in silence.

The day you find out that a client has died place two pieces of paper in your pockets. In your left pocket the paper might read, "some of my clients experience great sorrow." And in your right pocket the paper might read, "some of my clients experience great joy." Remember that you are in the middle experiencing both as you meet new clients and as others die.

Attend one of the volunteer support groups where you can meet and talk with other volunteers. Be intentional about realizing that you are alive and able to meet and laugh. Honor your clients who have died by living your life well.

Keep a small notebook where you record one or two memories from each client you meet. In just one or two sentences record your experience with them, what they taught you, what you learned about yourself, or what you would like to remember about them. Keep their confidentiality by not using their names.

When a client dies send good thoughts or prayers to the family. Intentionally think of what they are facing and wish them well.

Be intentional when signing a bereavement card. Take time to write an individual note in each. If you didn't really know the family, take time to imagine what might be supportive to them. Encourage them to take good care of themselves and remember that that is good advice for you too. When you close the card, you are also closing your time with the family. You can let them go. —Carol Kummet, Former EvergreenHealth Hospice Bereavement Coordinator

Steps To Participate In Your Own Healing

Talk about what happened, how it felt to you. Find other people who understand.

Talk about your person. The good – the bad – the fun – the sad.

Laugh without guilt. If he or she survived you, wouldn't you want them to laugh?

Cry with abandon! Let yourself cry. Require yourself to cry. Set this up for yourself as a way to heal.

Exercise daily. Exercise provides a natural source of endorphins.

These are natural substances in our bodies, which appear to mediate our perception of pain.

Sleep as well as possible.

Eat well. Nourish your body in a healthy way.

Give yourself spiritual care. Go to the woods. Tend to your spirit. Go to church.

Commune with other people. Find a path for yourself.

Ask yourself periodically, "What am I going to do for myself that is special?"

Do some special tending to self. Your heart is broken – tend gently and lovingly to yourself.

Participate in support meetings or self-care classes offered to hospice volunteers!

Infection Control, Ethics, Policies, & Resources

INFECTION CONTROL

EvergreenHealth prioritizes preventing infections in patients, healthcare workers (including volunteers!), and visitors.



How Does A Volunteer Contribute To Effective Infection Prevention?

STAY HOME WHEN YOU ARE SICK.

Start with personal hygiene. Arrive to your shift with a clean body and clean hair.

Wash your hands thoroughly and often!

Do not volunteer anywhere where isolation precautions (contact, airborne, or droplet) are in effect.

Practice respiratory etiquette (wear a mask!).

Do not eat or apply cosmetics (including lip balm) in patient care areas

Keep your immunizations and TB risk assessments up to date.

Report exposures to the Volunteer Coordinators and Employee Health.

Follow standard precautions.

Standard Precautions

Standard precautions are what you should always do to keep yourself safe.

Volunteers NEVER touch needles or other sharps.

Standard precautions are infection control guidelines designed to protect you from exposure to diseases spread by blood and certain body fluids.

Observe standard precautions when there is a potential for contact with blood or other infectious material. Treat all human blood and certain body fluids as if they are infectious. If differentiating between body fluid types is difficult, consider all body fluids infectious.

Volunteers who may be in direct contact with body substances must be protected by gloves and protective equipment before performing any tasks.

If in doubt, consult your position training or ask a Volunteer Coordinator, or patient's team member for guidance.

In case of a spill of blood or bodily fluids at the hospital or hospice center, call Housekeeping/Environmental Services (425) 899-6340. Do not touch or attempt to clean the spill. If you are exposed to blood or body substances, notify a hospice volunteer coordinator immediately. If they are not available, call Employee Health (425) 899-2282. If the exposure occurs after hours call the EvergreenHealth switchboard (425) 899-1000 and ask for the Nursing Supervisor.

Specimens: Volunteers must wear single-use latex or non-latex gloves when transporting specimens. Specimens must be sealed in a Biohazard bag and placed in a plastic bin for transport. Gloves are to be disposed of when transportation of specimen is finished.

Laundry: All laundry is to be handled as though contaminated or soiled. Gloves must be worn when handling soiled laundry. Laundry should never be placed on the floor or carried next to the body. Gowns can be worn to protect personal clothing.

Personal protection equipment: (PPE) protects you and will be provided to you. Volunteers are required to use appropriate protective equipment for any task that has the potential for exposure. Once used, all protective equipment must be removed, disposed of, and replaced.

Respiratory Etiquette

Developed by the CDC to reduce the transmission of respiratory pathogens, including flu, whooping cough, and SARS. The basic steps of respiratory etiquette are:

Cover your nose and mouth when coughing or sneezing. Turn away and cough/sneeze into your armpit or elbow.

Surgical masks will be available to you to use if the patient and/or caregiver are coughing. Masks will be available to them, too.

Hand sanitizer will also be available for you.

If you are sick with a respiratory illness, stay home.

Masks: Do not wear mask hanging under chin, on top of head, on your arm or neck. Wearing a mask is not required while eating or while working alone in a private office. Change the mask when: Mask becomes wet or soiled, Mask is worn more than 2 hours, Leaving any isolation room/area and/or Going from a patient care area to a non-patient care area

Hand Hygiene: Anyone working in hospice needs to regularly wash their hands. Studies have shown that the bacteria that cause healthcare-associated infections are most frequently spread from one patient to another on the hands of healthcare workers. Hand washing is the single most important and most effective way of preventing the spread of infection. Artificial nails can harbor bacteria even after hand washing and are therefore not allowed. Natural nails can be up to ¼" long. Nail polish needs to be chip-free, as bacteria can hide out just about anywhere. Jewelry on the hands and wrists is fine, bearing in mind that the more jewelry you wear, the easier it is for bacteria to hide out.

When To Wash Your Hands

- When coming on duty
- Before going into a patient's home or room
- Before and after touching the patient
- Before putting on gloves and after taking them off
- Before reaching into your PPE bag
- After touching contaminated objects (equipment, laundry, etc)
- After leaving a patient's room
- Before eating
- After using the restroom
- At the end of the shift
- After you leave the patient's home and before you enter your car

Hand Decontamination With Hand Sanitizer: If your hands are visibly dirty or you have been around diarrhea or vomiting, use soap and water to clean your hands. Hand sanitizer will not be up to the job!

Use Alcohol-Based (At Least 61%) Hand Rub

Squeeze a quarter sized amount on to one palm.

Rub your hands together, make sure to include the top, in-between your fingers, and under your nails. Don't forget your wrists!

Keep going until your hands are completely dry.

If your hands feel as if there is build up on them from using the alcohol-based rub, feel free to switch to soap and water.

Hand Washing with Soap and Water: Use soap and water when your hands are visibly dirty or if you have been exposed to GI symptoms (diarrhea or vomiting).

Wet hands and apply soap and rub hands together vigorously; avoid use of hot water because repeated exposure to hot water may increase risk of dermatitis.

Wash hands for at least 20 seconds covering all surfaces of the hands and fingers (remember your wrists!).

Rinse with water and dry the hands with a disposable towel from the fingers toward the forearm.

Use a dry disposable/paper towel to turn off faucet.

BLOODBORNE PATHOGENS

What are Bloodborne Pathogens?

They are bacteria, viruses and other microorganisms that are carried the bloodstream and may cause disease. Some bloodborne pathogens can be deadly. Some bloodborne pathogens that are the greatest risk to you are:

Hepatitis B Virus (HBV): Spread by contact with the blood of an infected person or by sex with infected person. A vaccine can prevent HBV.

Hepatitis C Virus (HCV): Liver disease caused by the hepatitis C virus, which is found in the blood or persons who have this disease. The infection is spread by contact with the blood of an infected person.

Human Immunodeficiency Virus (HIV): Spread by contact with the blood or other potentially infectious materials of an infected person or by sex with infected person

Bloodborne Pathogen Exposure: In the extremely unlikely event that you have an exposure to blood or substances considered potentially infectious for HIV, Hepatitis B and C while volunteering, post exposure treatment will be provided. In all patient-care activities, hospice volunteers can decrease the risk of acquiring or transmitting infection by careful hand washing and using Standard Precautions. All blood and body fluids are potentially infectious.

Exposures include but are not limited to:

Puncture wound from a needle or sharp instrument contaminated with blood or other potentially infectious material (OPIM).

Inoculation of conjunctivae with blood or OPIM. (eye splash).

Inoculation of oral mucosa (mouth) with blood or OPIM.

Cutaneous (skin) contamination with blood or OPIM.

What to do if you have an exposure while volunteering: IMMEDIATELY REPORT THE INCIDENT to a hospice volunteer coordinator or hospice manager; if unavailable or after hours, report to the Nursing Supervisor 425.890.4328; will receive further instructions.

Immediately Report To The Emergency Department For:

1. Known-positive exposure or high-risk patient (EHMC Emergency Dept)
2. When volunteer wishes to begin chemoprophylaxis, (EHMC Emergency Dept)
3. When the injury requires medical attention (closest Emergency Dept)

The emergency department provides treatment as warranted by the injury. Exposures requiring medical intervention are labor and industry claims. —EvergreenHealth policy: EHCS IC 9-004 Exposures in Personnel

What Is HIV?

FROM HIV.GOV: HIV (human immunodeficiency virus) is a virus that attacks cells that help the body fight infection, making a person more vulnerable to other infections and diseases. It is spread by contact with certain bodily fluids of a person with HIV, most commonly during unprotected sex (sex without a condom or HIV medicine to prevent or treat HIV), or through sharing injection drug equipment. If left untreated, HIV can lead to the disease AIDS (acquired immunodeficiency syndrome). The human body can't get rid of HIV and no effective HIV cure exists. So, once you have HIV, you have it for life. Luckily, however, effective treatment with HIV medicine (called antiretroviral therapy or ART) is available. If taken as prescribed, HIV medicine can reduce the amount of HIV in the blood (also called the viral load) to a very low level. This is called viral suppression. If a person's viral load is so low that a standard lab can't detect it, this is called having an undetectable viral load. People with HIV who take HIV medicine as prescribed and get and keep an undetectable viral load can live long and healthy lives and will not transmit HIV to their HIV-negative partners through sex. In addition, there are effective methods to prevent getting HIV through sex or drug use, including pre-exposure prophylaxis (PrEP), medicine people at risk for HIV take to prevent getting HIV from sex or injection drug use, and post-exposure prophylaxis (PEP), HIV medicine taken within 72 hours after a possible exposure to prevent the virus from taking hold.

What is AIDS?

AIDS is the late stage of HIV infection that occurs when the body's immune system is badly damaged because of the virus. In the U.S., most people with HIV do not develop AIDS because taking HIV medicine as prescribed stops the progression of the disease. A person with HIV is considered to have progressed to AIDS when:

the number of their CD4 cells falls below 200 cells per cubic millimeter of blood (200 cells/mm³). (In someone with a healthy immune system, CD4 counts are between 500 and 1,600 cells/mm³.) OR

they develop one or more opportunistic infections regardless of their CD4 count.

Without HIV medicine, people with AIDS typically survive about 3 years. Once someone has a dangerous opportunistic illness, life expectancy without treatment falls to about 1 year. HIV medicine can still help people at this stage of HIV infection, and it can even

be lifesaving. But people who start HIV medicine soon after they get HIV experience more benefits—that's why HIV testing is so important.

How Do You Get or Transmit HIV?: You can only get HIV by coming into direct contact with certain body fluids from a person with HIV who has a detectable viral load. These fluids are:

- Blood
- Semen and pre-seminal fluid
- Rectal fluids
- Vaginal fluids
- Breast milk

For transmission to occur, the HIV in these fluids must get into the bloodstream of an HIV-negative person through a mucous membrane (found in the rectum, vagina, mouth, or tip of the penis), through open cuts or sores, or by direct injection (from a needle or syringe). People with HIV who take HIV medicine as prescribed and get and keep an undetectable viral load can live long and healthy lives. HIV is not spread by:

- Air or water
- Mosquitoes, ticks, or other insects
- Saliva, tears, sweat, feces, or urine that is not mixed with the blood of a person with HIV
- Shaking hands; hugging; sharing toilets; sharing dishes, silverware, or drinking glasses; or engaging in closed-mouth or "social" kissing with a person with HIV
- Drinking fountains
- Other sexual activities that don't involve the exchange of body fluids (for example, touching).
- Donating blood

HIV can't be passed through healthy, unbroken skin.

Risk To Health Care Workers: The risk of transmission in a health care setting is extremely small if Standard Precautions, as mandated by WSHA, OSHA and recommended by the CDC, are followed each and every time.

HIV is not spread through day-to-day casual contact in the workplace.

HIV cannot be passed through the air.

Sneezing, breathing, and coughing do not spread HIV.

Touching, hugging, and shaking hands do not spread HIV.

No cases of HIV transmission have been linked to sharing typewriters, food, telephones, paper, water fountains, swimming pools, bathrooms, desks, office furniture, toilet seats, showers, tools, equipment, keyboards, coffee pots, or eating facilities.

HIV transmission is not possible from food in a restaurant being prepared or served by an HIV-positive employee.

Hepatitis B

Hepatitis is the inflammation of the liver and may be caused by many things, including viruses. There are several types of viral hepatitis (A, B, C, D, and E), but Hepatitis B presents the greatest risk to health care workers in the United States. Hepatitis B infections can have serious consequences including severe liver damage, long-term active hepatitis and cirrhosis of the liver. Long term carriers are at increased risk of developing liver cancer.

Most common cause of chronic viremia (viral blood infection)

200-300 million carriers worldwide

80% of primary liver cancer is caused by hepatitis B

50% of adults are asymptomatic

10% of those with hepatitis B progress to chronic infection

It is vaccine-preventable disease

Cause: Hepatitis B is caused by the Hepatitis B virus (HBV). It is primarily a blood borne infection.

Transmission: HBV is transmitted in the same ways as HIV through exposure to body fluids.

Vaccine: A hepatitis B vaccine is strongly recommended for persons at risk of HBV infection, including healthcare workers. It is a noninfectious product. It is safe and effective in the prevention of an HBV infection. The three-injection schedule will provide protective antibodies in over 90% of healthy adults and teenagers.

Tuberculosis

How TB spreads: TB bacteria spread through the air from one person to another. When a person with TB disease of the lungs or throat coughs, speaks, or sings, TB bacteria can get into the air. People nearby may breathe in these bacteria and become infected.

TB is NOT spread by

Shaking Someone's Hand

Sharing Food or Drink

Touching Bed Linens or Toilet Seats

Sharing Toothbrushes

Kissing

When a person breathes in TB bacteria, the bacteria can settle in the lungs and begin to grow. From there, they can move through the blood to other parts of the body, such as the kidney, spine, and brain. TB disease in the lungs or throat can be infectious. This means that the bacteria can spread to other people. TB in other parts of the body, such as the kidney or spine, is usually not infectious. People with TB disease are most likely to spread it to people they spend time with every day. This includes family members, friends, and coworkers or schoolmates.

TB Risk Factors: Some people develop TB disease soon after becoming infected (within weeks) before their immune system can fight the TB bacteria. Other people may get sick years later, when their immune system becomes weak for another reason. Overall, about 5 to 10% of infected persons who do not receive treatment for latent TB infection will develop TB disease at some time in their lives. For persons whose immune systems are weak, especially those with HIV infection, the risk of developing TB disease is much higher than for persons with normal immune systems. Generally, persons at high risk for developing TB disease fall into two categories:

Persons who have been recently infected with TB bacteria

Persons with medical conditions that weaken the immune system

Persons Who Have Been Recently Infected with TB Bacteria: Close contacts of a person with infectious TB disease

Persons who have immigrated from areas of the world with high rates of TB

Children less than 5 years of age who have a positive TB test

Groups with high rates of TB transmission, such as homeless persons, injection drug users, and persons with HIV infection

Persons who work or reside with people who are at high risk for TB in facilities or institutions such as hospitals, homeless shelters, correctional facilities, nursing homes, and residential homes for those with HIV

Persons with Medical Conditions that Weaken the Immune System: Babies and young children often have weak immune systems. Other people can have weak immune systems, too, especially people with any of these conditions:

- HIV infection (the virus that causes AIDS)
- Substance use disorder
- Silicosis
- Diabetes mellitus
- Severe kidney disease
- Low body weight
- Organ transplants
- Head and neck cancer
- Medical treatments such as corticosteroids or organ transplant
- Specialized treatment for rheumatoid arthritis or Crohn's disease

Tuberculosis (TB) screening and testing of health care personnel is recommended as part of a TB Infection Control Plan and might be required by state regulations. For TB regulations in your area, please contact your state or local TB control program.

Volunteer TB Testing: Prospective volunteers are required to have a TB test. All active volunteers fill out an annual TB Risk Assessment annually. If you have been exposed to anyone with TB or experience any symptoms of active TB, you should immediately report your symptoms and promptly be tested for active TB. You should monitor your own health carefully. TB screening programs should include anyone working or volunteering in healthcare settings, including:

- Inpatient settings
- Outpatient settings
- Laboratories
- Emergency medical services
- Medical settings in correctional facilities
- Home-based health care and outreach settings
- Long-term care facilities
- Clinics in homeless shelters

All U.S. health care personnel should be screened for TB upon hire (i.e., preplacement). The local health department should be notified immediately if TB disease is suspected. Annual TB testing of health care personnel is not recommended unless there is a known exposure or ongoing transmission.

WHEN TO STAY HOME

Work Restriction Policy

Persons with an infectious disease (or who are susceptible and exposed to an infectious disease) shall be restricted from direct contact with patients when:

- Transmission of the disease can occur in that particular job environment
- The disease can cause serious illness

As part of the initial health clearance, volunteers are required to get a Tdap (whooping cough) immunization. They also are required to get a flu shot each fall. There is a zero tolerance policy regarding volunteers working with a fever or an uncontrolled cough. However, in the event of accidental person-to-person transmission or an illness or an outbreak, appropriate follow up can be received in Employee Health.

Stay home if you have:

Fever of 100.5 or more, by itself or with cough, runny nose, sneezing, sore throat, swollen glands.

Eye infection

Vomiting

Diarrhea (more than one loose stool per day)

Uncontrollable cough

Undiagnosed rash with or without a fever

If you think you are in the early stage of an infectious disease

If You Are Already At Your Shift Or The Patient's Home:

Take protective measures to prevent transmission

Go home as soon as possible

Employee Health or Infection Control may be consulted if there are any questions

A physician's release and approval by Employee Health may be required for a volunteer to return to work after an illness.

Personal Protective Equipment (PPE)

Patient Care Activities

Protective Devices

	Hand Washing	Gloves	Gown	Mask
Bed change, visibly soiled	X	X	S	
Coughing patient, forceful and/or productive—direct contact	X			X
Direct contact with bodily fluids	X	X	S	M
Post-mortem care	X	X	S	

Legend: X = Use routinely S= Use if soiling likely M = Use if splattering likely

Putting on PPE

1. Sanitize HANDS (sanitizer or soap & water)

2. Put on GOWN: Fully covered, wrap around the back, fasten in back at neck and waist.

3. Put on MASK: Secure ties or elastic band at middle of head and neck. Fit flexible band to nosebridge and fit snug to face below chin.

4. Sanitize Hands (Sanitizer Or Soap & Water)

5. Put On Gloves: Pull glove up to cover wrist of gown (if applicable)

Removing PPE

Remove PPE at doorway before leaving patient room/home.

1. Remove gloves

Outside of gloves are contaminated

Grasp outside of glove with opposite gloved hand; peel off

Hold removed glove in gloved hand

Slide fingers of ungloved hand under remaining glove at wrist

2. Remove gown

Gown front and sleeves are contaminated!

Unfasten neck, then waist ties.

Remove gown using a peeling motion; pull gown from each shoulder toward the same hand- Gown will turn inside out.

Hold removed gown away from body, roll into a bundle and place in discard in waste container in patient's room (facility/HCC) or at their home (Home Care).

Sanitize hands (sanitizer or soap & water, as appropriate)

3. Remove mask

Front of mask is contaminated – DO NOT TOUCH!

Grasp ONLY bottom then top ties/elastics and remove

Discard in waste container in patient's room (facility/HCC) or at their home (Home Care)

Sanitize HANDS (sanitizer or soap & water, as appropriate)

Infection Control And Your Personal Items

Cell Phone, Laptop, Tablet, etc. (Probably MOST common way bacteria are passed from your hands to your patients)

Wipe keyboard with alcohol wipe ONLY at the beginning of the day, at the end of each visit and end of the day

Wipe cell phone if used during a visit

Allow alcohol to dry before putting the item away

Always place a barrier (pink drape, paper towel, your lap) under your laptop/tablet in a client's home.

Never place a barrier on the floor!

Backpacks, purses, etc., must have a barrier placed under it or hang it on back of chair or door knob.

Barriers may not be placed on the floor! Rolling bags/backpacks with wheels must remain on the floor

Alcohol Wipes VS. Bleach Wipes

Alcohol wipes – Allow items to dry before placing back in your bag: Laptop keyboards, Cell Phones, Tablets

Bleach wipes – wait 4 minutes and, if dry, place equipment back in your bag: Patient has any GI symptoms (vomiting/diarrhea)

Hand hygiene!

Place laptop, tablet, cellphone, etc., on a barrier (lap, pink drape, paper towel)

Place barrier on table, chairs, rolling bag but NEVER on the floor

Remember hand hygiene before entering PPE bag each time!

Medical Ethics

Ethics are the moral principles that govern a person's behavior and conduct. Medical ethics is the discipline of evaluating the merits, risks, and social concerns of activities in the field of medicine. Ethical dilemmas occur when there are differing opinions regarding a moral choice, or when there is a conflict of values or ethical principles. Bioethical principles you may encounter in hospice care are:

Beneficence: What choice is of the greatest benefit to the patient

Non-maleficence: The responsibility to do no harm

Autonomy: The patient's right to choose

Justice: Equitable treatment for all cases

Fidelity: The commitment to not knowingly lie

Ethical dilemmas develop when two or more ethical principles are in conflict, and there is value in each. When reasonable people do not agree and there are qualitatively strong arguments for each position, there is an ethical dilemma. For example:

A patient may refuse all medication and be in tremendous, unrelenting pain. The treating clinicians know that there are medications that will relieve the pain. The patient's choice (autonomy) conflicts with doing what is medically best for them (beneficence).

A patient's family asks that the patient not be told they are on hospice, as their culture believes that such knowledge will hasten the patient's death. The patient asks for their prognosis. In this instance, there is a three-way conflict between the patient's autonomy (right to choose), non-maleficence (do no harm), and fidelity (truthfulness).

ETHICAL DILEMMAS IN HOSPICE CARE

Treatment in hospice is not simply between a patient and a physician. The team effort is among the patient, their family, significant others, physicians, and clinicians. In addition, there is a multitude of questions about how a person may die and the variety of treatments and technologies that are available. There is a great deal of room for ethical dilemmas as the hospice staff member interacts with the community surrounding the patient and deals with the needs and desires of a particular patient. In addition to patient-related concerns, a staff member may face ethical questions involving work-related circumstances. In a two-year study of ethical dilemmas discussed in a formal setting in VITAS Healthcare Corporation, a hospice provider that has a dozen clinical ethics committees, the most common patient-related and work-related issues facing hospice staff members were the following, which are presented in the order of frequency:

The question of suicide, assisted suicide, and euthanasia

Working with patients who have been admitted without a do not resuscitate (DNR) order

The question of whether to perform cardiopulmonary resuscitation (CPR) on a patient who does not have a signed DNR order or an advance directive stating that the patient does not want CPR

Withdrawal or withholding of nutrition/hydration

Family decisions to "prolong dying" versus an incompetent patient's previously expressed views

Patient autonomy versus patient safety and physical needs

The under diagnosing of potentially treatable problems

Treating a patient on a ventilator

Removing a patient's life support system

Conflicts with the patient's family or significant others

Concern that the nursing home facility is not providing adequate care for the patient

Ethics of being judgmental or accepting

Religious objections regarding the treatment or lack of treatment given to a particular patient

Conflict over whether to follow a patient's wish to be discharged from a hospice unit when the staff member feels that the primary caregiver is incompetent to take care of the patient

Family needs and nursing home placement

Pain medication-respiratory distress/consciousness-the question here being whether the pain is so great that it is necessary to adversely affect consciousness and cause some respiratory distress by the higher use of medications to suppress the pain. Is it better to control the pain or for the patient to be more alert?

Dealing with the request of a white patient to have no other race of staff caring for the patient at home

Deciding whether to honor a patient's request for total palliative sedation for "existential" reasons (i.e., psychological distress or suffering rather than uncontrollable physical pain)

- Suspecting that a patient or family caregiver is selling or sharing the medications provided by the hospice
- Having to go into a neighborhood recognized as dangerous in order to provide home care for a patient
- Being sexually harassed or sexually assaulted by a patient or family member

The Hospice Ethics Committee: Any of the issues above can become ethical dilemmas within a hospice program. Although the list is not exhaustive, it is representative. There are several potential approaches. It is possible to ignore the conflict or dilemma, and this solution is one that is applied on a regular basis in all health care settings. It is also possible for the staff member to discuss the issue with the team physician or medical director, with colleagues at a team meeting, or with a designated ethicist or risk manager. Finally, the staff member may bring the issue to one of the gatekeepers on the hospice ethics committee. However, not all hospices have an ethics committee. In this case, the staff member may choose to use the ethics committee of a hospital or nursing home if the patient-related issue is involved with one of these. Fortunately, more and more hospices are developing ethics committees, many of them along the lines recommended by the National Hospice and Palliative Care Organization. These guidelines include the development of a committee that draws members from the team, from the hospice management, and from the community at large. The committee members receive training in ethical theory and the principles of ethics. These committees meet regularly to provide education on ethical issues and concerns to their members, to the hospice staff, and to the community. They use case study methods and often seek a consensus by applying the major principles of beneficence, justice, autonomy, non-maleficence, veracity, and values. By studying the principles and working together with cases, they can answer the question of what makes a particular issue an ethical dilemma.

Medical Aid in Dying with Dignity: The Washington Death with Dignity Act, or Initiative 1000, was passed in 2008 and went into effect in March 2009. The law allows eligible patients to ingest a lethal dose of medications after following a proscribed set of steps. EvergreenHealth assumes a neutral position, supporting patients and allowing them autonomy in making this decision, but referring them to End of Life Washington for education and guidance.

EvergreenHealth policy prohibits patients from ingesting the medication in any EvergreenHealth facility, which includes the Hospice Care Center. However, some EvergreenHealth Hospice Home Care patients choose to follow through and take the medications in their homes.

If a patient is considering Medical Aid in Dying, that information will be included in the Volunteer request form. If your patient brings up Medical Aid in Dying for the first time, listen with an open mind, refer them to their hospice social worker for further discussion, and make sure to include it in your visit note. Our hospice staff and volunteers are allowed to be present for this process, but only if they are invited and are comfortable being there. If you are asked to be present AND you wish to be, please discuss this with your team's social worker and/or the Volunteer Coordinators. We want to help prepare, as well as provide support to you before and after.

EvergreenHealth Hospice Volunteer Program Procedures And Regulatory Information

Rules, policies, and procedures ensure that we comply with federal, state, and local government regulators and regulations, including:

- Joint Commission on Accreditation of Healthcare Organizations (The Joint Commission)
- Center of Medicare/Medicaid Services (CMS)
- Department of Health (DOH)
- Occupational Safety and Health Administration (OSHA)
- Washington Industrial Safety and Health Act (WISHA)
- HIPAA, Confidentiality, and Personal Privacy
- Patient's Bill of Rights
- Security of Property
- Patient Safety and the National Patient Safety Goals

Standard (or Universal) Precautions, Infection Control, Hand Hygiene, and Respiratory Etiquette. You may have personal and/or professional experience or knowledge that goes beyond our training. If you are tempted to do anything other than what we have told you or shown you how to do, please ask first!

Accidents and Injuries: Any accident or injury needs to be reported immediately to a hospice volunteer coordinator or the Administrator on Call (425.899.1070) if you can't reach a coordinator; or you may go directly to the EvergreenHealth Emergency Department. Also refer to the INSURANCE section.

Identification Badge: Photo identification is required while performing all volunteer work for EvergreenHealth Hospice, and when attending functions where you are representing Hospice. It identifies you being part of the EvergreenHealth Hospice team. Always keep your badge in your physical possession or a secure location. The badge is the property of EvergreenHealth and should be protected from damage. Do not draw on it or add stickers or anything else to your badge.

New volunteers: You will get your badge from Human Resources. Once you have completed your onboarding process and are an active volunteer, we send you to HR with a badge form. They will take a photo (often a closeup!) and issue your badge.

Replacing lost badges: Lost picture IDs may be replaced with a form signed by a Volunteer Coordinator. Human Resources will reissue photo IDs with this signed form.

Taking a Leave of Absence or resigning: Please return your badge to a volunteer coordinator. If you are taking a leave, your badge will be placed in your file, so you don't have to replace it when you return to active volunteering.

Counseling: If a volunteer has performance problems, unsatisfactory behavior, has violated rules, or has not followed procedures, the hospice volunteer coordinator or their manager will counsel the volunteer. If the situation includes theft, vandalism, insubordination, or chronic absences without explanation, it may result in dismissal.

Dress Code: EvergreenHealth Home Care Services is committed to establishing and maintaining an environment that reflects quality care, professionalism, and hospitality. Accordingly, volunteers are expected to be neat, clean, properly groomed and identified to present themselves in a manner that reflects professionalism, competence, and caring. Volunteers are expected to be properly attired and ready to work at the beginning of their shift and throughout the whole shift. The dress code is in effect seven days a week. Volunteers may be asked to go home unless properly attired. Volunteers are identified by visibly wearing their hospital-issued I.D. badge when representing EvergreenHealth Hospice.

Daily Grooming Hygiene: This includes the use of antiperspirant/deodorant. Body odor should not be apparent. The smell of tobacco on clothing is unacceptable and fragrances (perfume, oil, lotions, etc.) should be avoided due to sensitivities of staff, patients, and families. Nails should be clean and should be kept neatly trimmed. Artificial nails are prohibited for direct patient care staff. Natural nails must be kept less than 1/4" long for patient care staff. Nail polish is fine if it is not chipped or cracked. Hair should be clean and neat. If it is long, it can be tied back or pinned up if it presents a safety measure or health hazard (i.e. it might drag across the patient). Facial hair clean and neatly trimmed.

Acceptable clothing items include:

Pants or skirts considering weather and patient's/client's home environment.

Skirts or dresses should be no shorter than touching just above the knee.

Loose fitting cropped pants that are no shorter than mid-calf.

Shoes appropriate for weather, clean/low cut athletic shoes.

Non-distressed denim

Any of the following items are considered inappropriate for professional wear:

Clothing that is lightweight or tight enough to reveal undergarments

Soiled, ripped, torn or clothing with holes

T-shirts with slogans/advertisement

Clothing that exposes the midriff, cleavage, or undergarments

Shorts

Sandals in direct patient care areas

Shoes that pose a potential safety risk

Slippers (unless medically indicated with prior approval of supervisor).

Ball caps, bandanas are not acceptable indoors (unless medically indicated with prior approval of supervisor). Progressive correction action will be followed for non-compliance with the dress code.

Driving: Home Care volunteers who drive to their visits (drivers) must have their driving records approved annually and provide their current driver's license and proof of insurance. In addition to a point system, approval is based on criteria that includes, but is not limited to:

No major (*) or capital violation (**) in the past ten (10) years,

No more than one (1) at fault accident in the past three (3) years,

No more than one (1) moving violation in the past twelve (12) months or two (2) in three (3) years,

No more than one (1) accident and moving violation combined in the past twelve (12) months,

No more than two (2) accidents and moving violations combined in the past three (3) years.

(*) Major violation: includes driving while under the influence of drugs or alcohol, reckless driving resulting in bodily injury or property damage or negligent homicide.

(**) Capital violation: includes driving after a driver's license was suspended, murder or assault with a motor vehicle, theft of a motor vehicle, hit and run, operating a vehicle after the registration was revoked or using false or fictitious driver's license or registration plates.

Eating: Eating is prohibited patient care areas.

Emergency Response For Hospice Volunteers

The Hospice Care Center (HCC) and Plaza (the Hospice Administration Offices) are considered off-site facilities.

For Fire, Police or Medical Emergencies:

Activate alarm, if needed. FIRST dial 9-911 request police, fire, or ambulance for appropriate emergency response.

THEN dial 1199 (Hospital 911) and report the fire, police emergency. (If you are in the Plaza, call 9-911 only.)

Non-emergency security issues: call extension 1300 (escorts, vehicle jump-start, flat tire etc.).

For Other Emergencies: FIRST- Call 9-911, THEN call- 1199 (hospital 911)

Code Red- Fire: In A Fire Activate The Nearest Pull Alarm.

Call or designate someone to call 9-911 to report the fire (Code Red)

4. Call or designate someone to call 1199 (hospital 911) and report the Code Red and location. (Code Red, Hospice Wing 2).
5. Staff will shut off oxygen valves.
6. Once the above procedure is completed, leave the building through the nearest exit.

When initiating a code RED remember R.A.C.E. and P.A.S.S.

RACE (The important steps of the fire safety plan)

1. Rescue everyone in danger (if possible) Pull the pin.
2. Alarm the building by using a fire alarm pull station and call 9911 Aim at the base of the fire (stand back 10 feet).
3. Contain the fire by closing all doors Squeeze the handle.
4. Extinguish the fire (If possible) Sweep horizontally.

PASS (How to use a fire extinguisher)

It is essential to familiarize yourself with fire alarm pull stations, extinguisher locations, and exits.

The locations at the hospice care center:

Pull stations: Just inside main doors, across from the reception desk

1. Across from the Nurse's Station on Wing I
2. Family Rooms on Wing I and II
3. Outside the Family Kitchens on Wing I and II
4. Outside the Staff Lounge
5. Wall between Conference Room and By the exterior door outside the Reflection Room
6. Administrative Wing, far end of hall

Fire Extinguishers: Outside the Family Kitchen on Wing I Family Room and Kitchen

Near the Nurse's Station on Wing I, across from Room 4

Outside the Staff Lounge

Wing II Foyer

Outside the Wing II Nurse's Station

In the Facility Kitchen

Oxygen Valves: Medical Records (Celia's old office), Mechanical Room (next to the loading dock doors)

Fire Drills: In the event of a fire drill, follow the above procedure and be prepared, if asked, to verbalize the procedure, step by step. Additionally, once the above procedure is completed, leave the building through the nearest exit.

Code GRAY- Out of Control or Combative Person

If there is a physical fight between people outside Hospice call 9-911 first. Tell police you have people fighting/arguing and give location. Then call 1199 and report to security. If you have an out of control patient/visitor:

Dial 1199 call a Code Gray and give the location to the hospital operator. (example: Hospice wing 2 room 12)

Prior to a Code Gray, you can call 1199 and ask for security STAT

Code WANDER- Missing Patient/Person

Dial 1199 call Code Wander and give location. The operator will inform security of the code

Code BLACK- Bomb Threat

Dial 9-911 report the bomb threat to police

Dial 1199 report Code Black and give location to the operator

Code SILVER- Brandished Weapon Or Hostage Situation

Weapons are not allowed on EHMC grounds

If you see anyone with a weapon: Call security at 1199 and give proper information so Security can contact the person and explain our weapon policy

If someone is taken hostage or barricaded in a room: Call 9-911 and report to police a person with a weapon or a hostage/barricaded person. (Plaza occupants: Call 9-911 only). Call 1199 and report Code Silver and location: EvergreenHealth Hospice Center 12822 124th Lane N.E., Kirkland, WA, 98034 (*Clear the area of bystanders*)

Code BLUE- Cardiac Arrest Or Medical Emergency

Dial 9-911 and tell the operator you have a medical emergency and give the location. No Medical Staff from Evergreen Hospital respond to Code Blue incidents at Hospice or the Plaza

If there are crowd control issues at Hospice, call 1199 after calling 911 and ask for security to assist

Code ORANGE- Hazardous Materials Spill

A significant hazardous materials spill (more than a gallon of hazardous material), release or odor. Dial 1199 report a Code Orange and location. Secure the spill area from spectators and wait for emergency response.

Emergency Responses for Emergencies when Volunteering in Homes: If you do not feel safe, call 911 and then call hospice. Your safety is our first concern. If you cannot safely and quickly get your patient outside and/or away from danger, leave and then call 911 If your patient stops breathing while you are providing respite, call hospice and then the caregiver – unless the patient is FULL CODE. If they are FULL CODE, call 911 and then hospice. This will be discussed during Core Training.

Gifts: Please do not accept gifts from patients or caregivers. Suggest that they donate to EvergreenHealth Hospice Volunteer Fund through the Foundation and offer to bring a donation envelope to them.

GRIEVANCE PROCEDURE

Difficulties and problems arise in every workplace. To maintain a positive and mutually supportive workplace, volunteers are asked to bring any concerns to a hospice Volunteer Coordinator or the manager overseeing Hospice Volunteer Services. If you prefer to remain anonymous, you may write a message outlining your concerns, place it in a sealed envelope and send it to Hospice Volunteer Services, 12822 – 124th Lane NE; Kirkland WA 98034.

Holidays

Volunteering on a holiday is up to each hospice volunteer. If you will not be volunteering on a holiday, please follow the same procedure you would if you are unable to come in on a regular shift or home visit.

Illness: Refer to your position description on how to report an illness/absence. Immediately report any communicable disease such as Chicken Pox. To talk to a nurse at any time-- day or night-- or to get medical advice, call the EvergreenHealth line: 425-899-3000.

Insurance: EvergreenHealth provides general liability insurance and self-insured workers comp for volunteers, and secondary insurance for volunteers using a personal vehicle on EvergreenHealth's behalf. Report accidents and/or injuries immediately to a hospice Volunteer Coordinator or the Manager on Call (MOC) at 425.899.1070 if you can't reach a coordinator; or you may go directly to the EvergreenHealth Emergency Department. If you go to the emergency department during your shift, you will be asked for insurance information. Liability will be evaluated to determine if your insurance will be billed. A volunteer driver's personal automobile insurance is primary in the event of an accident. EvergreenHealth should be alerted to any accident that occurs during a volunteer's shift.

Mandatory Reporting

Abuse, Neglect, and Suicide: Hospice volunteers are mandatory reporters. Immediately report any suspicion of or reported incidences to hospice as described below.

Suicide - Definitions

Suicidal threat: Someone tells others that he or she is about to commit suicide

Suicidal plan: Someone has a plan to commit suicide

Suicide attempt: Someone tries to kill self but is not successful

Physician-assisted death (Death with Dignity): Someone has received a prescription from a physician to take his or her life. This is legal in the State of Washington and is not considered suicide

Abuse and Neglect - Definitions

Abuse: An act of physical or mental mistreatment or injury that harms or threatens a person through action or inaction by another person

Neglect: Conduct resulting in deprivation of care needed to maintain minimum physical and mental health

Abandonment: Leaving a vulnerable or dependent adult without means to obtain food, clothing, shelter, or health care

Exploitation: The illegal or improper use of a vulnerable adult or dependent person, or that person's resources, for another's profit or gain

Dependent adult: Person over 18 who is legally incompetent or disabled to the extent that protection under guardianship law is indicated

Vulnerable adult: A person 60 or older whose functional, mental or physical ability to care for self is impaired

If suicide, abuse, or neglect is suspected or reported, volunteers are to immediately report the incident (see below). This is required by law. The purpose of this is to intervene on behalf of the patient, but also for consultation, instruction, and support. You don't have to have evidence or direct observation before reporting an incident.

Volunteers at the Hospice Center: Inform a registered nurse and/or a social worker immediately

Home Care volunteers: At a facility (skilled nursing facility, assisted living facility), alert either the Nurse Manager or social worker for the unit or the social worker. Then notify EvergreenHealth Hospice using the same guidelines as below:

At a patient's home, report the incident immediately to a hospice case manager (social worker or nurse) AND to the Volunteer Coordinator

Document the incident and subsequent communication in your visit note

Call (425) 899-1070 or 1 (800) 442-4546 to report the incident to hospice

Religious Views: EvergreenHealth is a public hospital (a percentage of its income is from tax dollars) and, therefore, volunteers may not express unsolicited religious views to patients, visitors, staff, or other volunteers. Volunteers may not wear nametags of religious organizations. Hospice volunteers may pray, read from books of faith, and/or sing music of faith at the request of patients and/or families.

Sexual Harassment: All volunteers, staff, and visitors should be able to work in an environment free from all forms of discrimination, including sexual harassment. Sexual harassment is a form of misconduct, which undermines the integrity of the employment relationship. No one should be subject to unsolicited and unwelcome sexual overtones or conduct either verbally or physically.

Sexual harassment does not refer to casual conversation or compliments of a socially acceptable nature. It refers to behavior that is not welcome and which is personally offensive, interferes with work effectiveness, or creates uneasiness while volunteering. Such conduct is specifically prohibited. This includes repeated offensive sexual flirtations, advances or propositions; continuous or repeated

verbal abuse of sexual nature; graphic or degrading verbal comments about an individual or his/her appearance; the display of sexually suggestive objects or pictures; or any offensive or abusive physical contact.

Any such actions will bring prompt and certain disciplinary action, including possible termination.

Any volunteer who believes that she/he has been subjected to sexual harassment or intimidation while volunteering should bring this to the immediate attention of a hospice Volunteer Coordinator or their manager. All such complaints will be promptly and fairly investigated. All such complaints will be treated in the strictest confidence.

Smoking: Smoking is not allowed anywhere on the EvergreenHealth grounds. EvergreenHealth is a non-smoking campus.

Substance Use: The unlawful manufacture, distribution, dispensation, possession, or use of intoxicants, drugs, or controlled substances is strictly prohibited in our workplace. This includes reporting to work under the influence of intoxicants, drugs, or controlled substances.

Corporate Compliance

Compliance Officer and Committee regulate patient rights, confidentiality, financial reporting, gifts, gratuities, policies, and procedures

Ethics Committee

Formal Policies include Code of Conduct, Harassment Free Workplace Environment, Confidentiality, Professionalism and Ethical Behavior, Anti-Kickback, Whistleblower Protection Act, among others

Training & Education

Hotline for Reporting Incidents: 425-899-5599

Volunteer Responsibility

Report errors, problems, and near misses. By doing this, it:

Helps identify system problems and opportunities to improve

Allows tracking and trending

Allows us to identify “near misses” or “good catch” situations, which helps prevent errors

Event reports are processed by managers and supervisors. They are confidential and protected by State Law. They are non-discoverable in a legal process and never placed in personnel files.

HIPAA: HEALTH INSURANCE PRIVACY & ACCOUNTABILITY ACT

The original purpose of the Health Insurance Portability and Accountability Act (HIPAA) was to make it easier for people to move from one insurance plan to another as they changed jobs or became unemployed.

Why are privacy and confidentiality important?

Patients have the right to control who will see their protected health information. This means that any type of communication (verbal, written, or electronic) that includes protected health information must be kept private and limited to those people who need the information for treatment, payment, and/or healthcare operations purposes. Respect the privacy of all of our patients. If in doubt, ask one of the hospice Volunteer Coordinators.

What is considered confidential information? Confidential information includes patient identity, address, age, social security number, and any other personal information that they are asked to provide. It includes any information that may identify the patient. It also includes the reason a person is sick or in the hospital, the treatments and medications he or she receives and any other information about his or her condition or past health conditions. Even after the patient has died you must keep their information private.

How is patient information used? Patient information is used for the care of patients.

Who is authorized to see patient information? Only people who need access to confidential information in order to do their job will see patient information. Volunteers who have computer privileges should not attempt to gain access to patients that are not part of their assignment. They also should not attempt to find out information that is not relevant to their role. Volunteers at the hospice center should not try to find out information not provided to them as part of their volunteer role. Whatever you see, hear or read in the course of your volunteering cannot be shared with anyone, unless it has to do with the care or safety of the patient. Protecting confidential information is a responsibility that the entire workforce shares, including volunteers, regardless of whether they are directly involved in the care of patients.

Case Scenario #1 You've heard on the news that a famous person is in the hospital.

Q: Is it okay for you to ask around or look for records about this person?

A: No. If you look at patient records to satisfy your curiosity or for any other non-business reason, it is cause for dismissal and possible legal consequences.

Case Scenario #2 You find out that a neighbor or friend has been admitted to hospice (or to the hospital).

Q: Is it ok for you to tell your family or other neighbors?

A: No. Any information you learn as a result of your duties at EvergreenHealth needs to be kept private.

Confidentiality when using computers: Volunteers who use computerized patient records must lock their computers if they leave their workstation and log off when their shift is over.

Sanctions for Violating Privacy Rules: EvergreenHealth has policies regarding sanctions for members of our workforce who break our privacy policies, up to and including dismissal. In addition, there are potential civil and criminal penalties for breaking the HIPAA privacy or security rules. Civil Penalties are fines of \$100 per violation per person up to a maximum penalty of \$250,000 for each identical breach. Federal Criminal Penalties for wrongful disclosure include not only large fines, but also up to ten years in jail. These penalties can be levied against the individual as well as the organization.

Reporting Violations: You are encouraged to report violations or suspected violations to the Hotline number at 425-899-5599. You may report anonymously, if you wish.

Confidentiality Of Patient Care

Confidentiality involves honoring the trust a person places in us. Active listening and compassionate presence put us in close relationship with hospice patients, as well as their families and friends. They may share intimate, personal details of their lives with us. The purpose of the HIPAA and Evergreen's confidentiality policies is to make sure that those who have access to patient/family confidential information will safeguard this information.

We do this in the following ways:

MAINTAIN CONFIDENTIALITY of all protected health information (PHI) in any form – written or electronic – as well as in oral and electronic conversations, including texting and social media. PHI includes personal, medical, and financial information, and photos. Anything you see, hear, or read is private and is to be protected.

VOLUNTEERS ARE NOT ALLOWED TO PHOTOGRAPH OR VIDEO any patient at any time with their phone, camera or other device. Violations may result in dismissal.

Confine mentioning of patient/family names to contacts with the Hospice team. USE DISCRETION even when sharing with a team member. Free exchange of patient confidential information is allowed between EvergreenHealth Hospice employees and affiliated agencies, and between paid and unpaid staff only when that information has bearing on the patient's treatment plan. Never promise a patient/family that you will not tell anyone any piece of information shared with you. You are part of a team!

Remember that it's a small world. Information concerning friends or acquaintances on the census or request list, or that you see in the hospice center or hospital is confidential.

BE AWARE OF YOUR SURROUNDINGS. Share information only in areas where you cannot be overheard. A seemingly obscure reference may be recognized by someone when you least expect it.

Home Care & Tuck-In Volunteers: Never leave written documentation/communication that contains PHI in visible places. Have a secure place to keep it while you are assigned to the patient or making calls. After the patient has died, has been discharged from Hospice, or your weekly calls have been made, shred all written documentation. Do not store electronic documentation/communication on your personal computer.

REPORT ANY KNOWN OR SUSPECTED BREACHES, OR LOSSES OF PATIENT INFORMATION immediately to a volunteer coordinator or to the Privacy Officer at (425) 899-5599. Any unauthorized disclosure of confidential information could render the institution liable for damages on grounds of defamation or invasion of the right to privacy.

The Importance Of Confidentiality Cannot Be Overemphasized!

BREACH OF CONFIDENTIALITY IS SUFFICIENT CAUSE FOR IMMEDIATE DISMISSAL FROM VOLUNTEER STATUS.

Social media and patients (A Dangerous Interaction): Even though we increasingly lead our lives on social media, you need to be careful about anything you post online that might expose any patient information. Federal and state law require you to keep patient information confidential, and it's easy to make mistakes.

Problems arise not necessarily because people are careless, but because they care a lot. Healthcare work can be challenging, with long hours and difficult patients, and it can be tempting to talk about patients. Healthcare work is also rewarding, and you may develop close relationships with patients and families.

Never forget that the information you get as part of volunteering with hospice is confidential and should not be shared on social media. Federal law requires this!

What is prohibited?

- Posting pictures of patients
- Complaining about patients or mentioning patients while complaining about your job
- Blowing off steam after a hard day, such as posting about a difficult experience with a very sick patient
- Commenting on news stories about patients who are being treated at the facility
- Letting people know that a celebrity, politician, or other prominent person is being treated at our facility
- Adding information to threads others have started

The Health Insurance Portability and Accountability Act (HIPAA) protects healthcare information related to an identifiable individual. Even if just one person can identify the patient you are posting about, the post is identifiable. The chances of this happening are high—even if all of your privacy settings are turned on. Posting in private groups is also not allowed. On social media nothing is truly private.

Best practices Do not list our organization in your employment section.

- Do not reference events that happen while volunteering.
- Keep social media conversations with other volunteers limited to personal topics.
- Do not send pictures of patients to your friends or put them on social media.
- Do not engage with patients or caregivers on social media.
- Report inappropriate use to privacy@evergreenhealth.com or your supervisor.

Social media posts can be disciplined as privacy breaches: Multiple facilities have terminated employees after pictures of patients or nursing home residents were posted to social media sites like Facebook, Instagram, and Snapchat.

PATIENT SAFETY

Patient Safety is about ensuring that our patients and visitors are free from things that can cause harm within a medical setting. Harm is perceived by people in many ways. We cannot improve Patient Safety until we admit that we are human and mistakes do happen. We can learn from actual events where harm occurs and “near misses” - events that don’t cause actual injury to a patient, but could, given a different set of circumstances. In order for people to feel safe reporting mistakes we need to remove the blame from our system and allow people to feel that they will not be punished for coming forward with information about an error.

Some of the things that we do to prevent patient harm and injury are:

Policies and procedures

Orientation and training

Equipment safety checks

Building safety inspections

Reasons that result in harm or injury are that systems fail or break down. Processes are not perfect. EvergreenHealth strives to be a “just culture” – it’s not about “who did something wrong,” but about how a system or process failed and allowed an error to occur.

It is the policy of EvergreenHealth to ensure that its patients are cared for safely while maintaining a safe work environment for employees and volunteers; and to ensure compliance with Washington State HB 1672 – Safe Patient Handling legislation. Volunteers will follow directions and procedures and comply with policies. The purpose of The Joint Commission’s National Patient Safety Goals is to promote specific improvements in patient safety. The goals highlight problematic areas in healthcare and describe evidence- and expert-based consensus to solutions to these problems. Recognizing that sound system design is intrinsic to the delivery of safe, high-quality health care, the goals generally focus on system-wide solutions, wherever possible

Why Is Patient Safety Important?

Medical error is the 8th leading cause of death in the USA today (higher than breast cancer, AIDS, and motor vehicle accidents). Patients come in to receive care and trust that we will protect them and ensure they are safe. If that trust is broken, we all suffer- patients lose confidence and don’t seek the care they need, and that means that we aren’t able to continue bringing enough revenue in to serve them.

What is EvergreenHealth doing to keep patients safe? We educate all staff members, employed physicians and volunteers across all of our care settings. We implemented the National Patient Safety Goals that were put out by Joint Commission. Actual events that meet the definitions of Joint Commission and WSDH (Washington State Dept. of Health) are called Sentinel Events. Whenever we have this event, we are required to report to Joint Commission and to WSDH. Examples of Sentinel Events in hospice: medication error; equipment failure; suicide. We have a consistent way to approach planning, implementing, and measuring projects designed to improve our care and outcomes. ***The process is called Plan-Do-Check-Act or PDCA***

How Do Volunteers Keep Patients Safe?

Everyone has a role in keeping patients safe. We all can identify unsafe situations and take action to protect our patients. All volunteers have a Patient Safety Card with their ID badge. Report unsafe conditions by using the phone numbers listed on your badge.

Stopping the spread of infection is important – practice good personal and hand-washing hygiene, and follow Standard Precautions.

Keep your immunizations current.

Stay home when you are ill.

Patient Identification Policy: Each volunteer will use two patient identifiers when providing care, treatment, or services. The two most common patient identifiers are name and birthdate.

For Home Care Volunteers

At the first visit, the volunteer will use 2 patient identifiers; Patient Name and Date of Birth to verify patient identity.

Procedure: Ask the patient (caregiver or family member if patient is nonverbal)

At subsequent visits, each staff/volunteer will use 2 patient identifiers; Patient Name and Facial Recognition to verify patient identity.

Procedure: Ask the patient (or caregiver or family member if patient is nonverbal)

For Hospice Care Center: Volunteers will use 2 patient identifiers; Patient Name and Date of Birth to verify patient identity. Volunteers may verify date of birth by viewing the name band on patient wrist.

Procedure: Ask the patient (caregiver or family member if patient is nonverbal) for name and date of birth OR LOOK at name band on patient's wrist.

Age-Specific Competency

The Joint Commission on Accreditation of Healthcare Organizations requires that all employees and volunteers who work with patients are aware of the differences in the age groups, as well as care considerations.

Age and Different Criteria Care Considerations

Neonate: Birth-6 weeks

- Risk for aspiration
- Overstimulates easily
- Development of the ability to rely on others
- Recognizes bright objects, black and white
- Neonate is developing a sense of trust vs. mistrust
- Position infant carefully
- Keep bulb syringe readily available
- Diminish or minimize stressors: lights and noise
- Proper education of parents
- Keep parents in line of vision
- Encourage parents to stay with neonate
- Encourage bonding with parents

Infant: 6 weeks-1 year

- High metabolic rate: gains weight/height rapidly
- Progresses to recognizing familiar objects and persons
- Communicate by crying and making simple sounds
- Trust vs mistrust
- Fear of strangers
- Provide consistent meal times and snacks
- Keep parents in infant's line of vision
- Involve parents in care of infant

Comfort infant when distressed

Significant persons are the parents or primary caregivers

Limit number of strangers present

Child: 1 year-17 years

Attention span is short

Comprehends, starts to view things from different perspective

Increased ability to use abstract reasoning and logic

Can understand simple directions

Needs 10-12 hours of sleep, may experience fatigue

Developing a sense of independence, moods and emotions change quickly

Focus on one thing at a time

May perceive hospital treatments as punishment

Encourage questions

Encourage rest times

Explain procedure in simple terms and allow time for questions

Adult: 18 years-65 years

Gradual increase in susceptibility to infections

Increased response to stress

May be dual caregivers

Significant stressors may be present-relationship, career, caregiver roles and financial

Encourage flu and pneumonia vaccines

Assess for physical and emotional stress

Assess for potential stresses, provide resources and support

Provide support to patient if feelings of frustration or disappointment

Geriatric: 65 years and beyond

Prolonged response to stress

·Slower in learning and understanding of new information

·Mood swings

·Increased concern for health

·Adapting to changes in social roles and supportive relationships

Monitor for increased anxiety or depression

·Use clear, low-pitched speaking

·Provide resources, include family and caregiver in teaching

·Explore patient's support system and involve them in care management

Code: Amber Alert

Newborn infant abductions have increased across the United States. Any hospital can be a target, regardless of size or location. The national oversight committee, The Joint Commission on Accreditation of Healthcare Organizations (Joint Commission) has uncovered the following facts:

- All infant abductions took place in large hospitals: in the mother's room, in the newborn nursery and in the newborn intensive care unit

- Most infants were recovered unharmed, most within a few hours

- All abductors were female and impersonated nurses, nurse's aides, physicians, volunteers, or the infant's mother

- Infants were abducted when taken for testing, during return to the nursery, when left unattended in the nursery or while a mother was napping or showering

It is the policy of EvergreenHealth to ensure that all hospital personnel and outside agencies are notified appropriately in the event of an infant abduction, to locate and reunite the infant with family as quickly as possible.

In the Pediatric Unit

Parents are instructed to inform the infant's nurse when they are leaving the room.

- If the parents are not in the infant's room, visitors must be listed in writing by the parents and show picture ID to verify who they are to the staff.

- Infants are always transported in a crib or isolette

- EvergreenHealth staff will always wear badge ID

- Always question unfamiliar or suspicious appearing people by asking if they need assistance

Volunteers' Responsibilities: It is your responsibility to know what to do quickly when a "Code Amber Alert" is paged overhead at the hospital.

- Watch exit doors on the premises and detain everyone until the "Code Amber Alert" has been cleared

- You may assist with any helpful descriptions (i.e. height, weight of person suspected, description of car, number of plate of suspected abductor's car, etc.)

- Volunteers may also assist in documentation on the code review sheet

ENVIRONMENT OF CARE

EvergreenHealth maintains two committees:

- Environment of Care Committee: Oversees the Environment of Care Plan so that it remains current with changes to the EOC standards of the Joint Commission for Accreditation of Health Care Organization.

- Safety Committee; Safety Committee members are elected to 1-year terms by each department. The Hospital Safety Officer and the Chairperson of the Environment of Care Committee are permanent members of the Safety Committee.

Security Management

Response to all security incidents (identification, hazardous spills, infant abduction, security).

- Safety and Security Services staff responds to all security incidents upon notification. All medical center staff, volunteers, patients, visitors, or other community members may report incidents or request security assistance.

- Security Services staff will document all reported and observed security incidents by completing Security Incidents Reports.

Staff and Volunteer Identification: EvergreenHealth uses badges for the identification of patients, visitors, staff, and volunteers:

Volunteers are issued photo identification badges. Hospital policy requires volunteers wear their badges at all times in a visible manner and in the event of termination of employment or service period, are required to return their badge. This is the best way to identify staff and volunteers. Personal identification is the best security.

Hazardous Materials and Waste Management Program: Department managers will maintain a written inventory listing all hazardous chemicals used within the department. The list will be available at all times.

Material Safety Data Sheets (MSDS)

Information is located in MSDS database at all times. These sheets list what is in the products they are using (products for housekeeping, clinical use, etc.). Important aspects include:

Container Labeling: All contents are clearly labeled, display the appropriate hazard warning, and list the name and address of the manufacturer, and include physical and health hazards. Do not remove or alter the labels. Always use the product as directed on the label.

Training and information: Volunteers receive general information about Hazard Communication and department-specific training. The department manager is responsible for department-specific training. Volunteers are given information about hazardous chemicals that they may be exposed to during their work.

Equipment Management: Radio frequency transmitting devices may interfere with medical devices. All employees are authorized to instruct any person to turn off radio transmitting devices and report concerns to the Biomedical Engineering Department.

Cellular phones and other wireless devices: Cellular phones and other similar devices (pagers, laptops, tablets, etc.) using cellular telephone technology may be used without restriction in all non-patient care areas of the hospital. Use of cellular telephones within patient care areas will be restricted within 3 feet of medical equipment that is currently in use for patient care, treatment or diagnosis.

Fire/Life Safety Program and Guidelines: The Hospital Fire Marshall and the Hospital Safety Officer have the authority to monitor and enforce the Fire Safety Guidelines. Volunteers, students, physicians and other independent practitioners will follow the specific instructions. All volunteers will observe and cooperate with the following fire safety guidelines:

- Exit corridors will be kept clear at all times
- Door wedges on Fire Doors are forbidden and staff is authorized to remove wedges
- Participate in fire drills, and safety and evacuation training
- Report all smoke/fire barrier doors that need repair to Plant Ops
- Do not allow doors to be blocked by equipment at any times
- Report any fire detection equipment that needs repair to Plant Ops

RACE (The important steps of the fire safety plan)

Rescue everyone in danger (if possible)

Alarm the building by using a fire alarm pull station and call 9911

Contain the fire by closing all doors

Extinguish the fire (If possible)

PASS (How to use a fire extinguisher)

Pull the pin.

Aim at the base of the fire (stand back 10 feet).

Squeeze the handle.

Sweep horizontally.

Utility Systems Program: Contaminated water, airborne diseases, sanitation. Volunteers will immediately report all utility system problems that pose a risk of disease transmission to the Plant Ops Department.

Emergency Management Program

EvergreenHealth maintains a written Emergency Management Plan that addresses the four (4) phases of emergency management; mitigation, preparedness, response and recovery. The Hospital Safety Officer is responsible for developing, implementing and monitoring the Emergency Management Plan. Key aspects of the emergency Preparedness Plan are reported to the Emergency Preparedness Committee and Environment of Care Committee in order to provide a coordinated hospital wide response to all emergencies and other issues.

Event Alert

It is the policy of EvergreenHealth to notify employees when emergency response measures are initiated. Upon becoming aware of an emergency situation that has the potential to impact patient care, employees will call the hospital operator (x1199) to initiate an Event Alert. The initiating employee will meet with the responding Event Alert Team in the Emergency Department. Hospital operators will immediately overhead page "Event Alert" per procedures.

Event Alert Level 3 – Wait for Instructions: Internal or External event that will not seriously disrupt the daily operations and may only require additional staffing in the Emergency Department or area(s) affected.

Event Alert Level 2 – One Person from Department to Manpower: Internal or external event that may exceed normal operations.

Event Alert Level 1 – Full Response by All Staff: Internal or external event affecting the daily operations that will exceed present resources of the organization.

- All volunteers that report to the hospital will be directed to the Labor Pool. All volunteers are expected to provide support in case of an emergency and may be called upon to do so during a crisis.

Violence In The Workplace

All employees/volunteers are hereby notified of EvergreenHealth's "zero tolerance" toward violence in the workplace.

Volunteers/Employees/Physicians: Any person who engages in violent behavior or threats, either verbal or non-verbal, is subject to appropriate disciplinary action including immediate termination of employment.

Patients/Visitors: Patients/Visitors who engage in violent or threatening behavior will be reported immediately to Security. The incident will be documented by Security. Visitors who are violent or threatening will be instructed to leave the premises. EvergreenHealth security officers will escort such person off the premises and may request assistance from the Kirkland police.

Assaulted Employee/Volunteer: Following an assault, the volunteer will notify his/her immediate supervisor. The volunteer will report to the Emergency Room for treatment of injuries. The volunteer(s) and/or witnesses will cooperate with security in completing the security incident report.

Chemical Hazard Training

In general, volunteers do not handle dangerous chemicals; however, some common products such as detergents or glass cleaner are considered hazardous and volunteers may handle them. Products should only be used as intended per the package labeling. There is a Material Safety Data Sheet (MSDS) for every hazardous product used within Evergreen. If you are ever asked to handle a product that you believe may be hazardous, ask your supervisor for the MSDS, which can be found on SharePoint. Your safety is our primary concern. As a volunteer, you are a valuable part of our organization and we are committed to ensuring you the safest environment possible. This includes your physical and emotional safety and well-being.

All EvergreenHealth Hospice team members are aware that volunteers only should be assigned to services that they can safely perform and you have the authority to refuse any request to perform service outside of your abilities and training provided by EvergreenHealth Hospice Volunteer Program.

As an EvergreenHealth Hospice Volunteer, you agree to the following.

Not to exceed your abilities while performing service for EvergreenHealth. Volunteers are to decline participation in activities that: They have not been trained to perform. They cannot lift or maneuver safely, whether due to ability or ergonomics. They might not be able to complete safely due to their emotional state. Promptly report any requests to perform services that is beyond your ability or training, or that you feel is unsafe to a Hospice Volunteer Coordinator. EvergreenHealth values your donation of time and wants to ensure your best interests are served. Thank you for your commitment to help us help keep you safe.

General Safety Guidelines

Open doors slowly to avoid collisions.

Keep aisles and corridors clear of obstructions at all times to provide clear and safe exits.

Use safe-lifting techniques. Get help lifting heavy or awkward loads.

Use a ladder or step stool. Do not substitute chairs or other items.

Cords will be kept out of aisles.

Drawers will be kept closed at all times when not in active use.

Follow Infection Control and Environment of Care guidelines related to:

- Control of Infection

- Bloodborne Pathogens

- Security

- Hazardous Materials and Waste

- Fire Prevention

- Electrical Safety

Personal Safety

Always wear your identification badge when volunteering.

General Precautions:

Know exactly where you are going.

Know the community where visits are being made.

Do not take personal safety for granted.

Keep alert to avoid becoming a victim of an attack or robbery. Look for the unexpected and avoid taking unnecessary chances.

Review concerns with a Volunteer Coordinator prior to the visit if the environment does not feel safe.

Leave the home as quickly as possible, and contact the office when safe, if an unsafe situation should arise during a visit.

Be sure your vehicle is in good working order and that you have sufficient fuel. Always keep all doors locked.

Consider having a spare set of keys in hospice bag/briefcase or keep keys in a magnetic holder hidden on the outside of the car. Locking keys in the car can happen unexpectedly.

Do not carry excessive amounts of cash. Do carry enough money for emergency transportation and phone calls.

If possible, avoid carrying a purse. If you do carry a purse and are driving, lock it in your trunk before you leave. Keep money and identification in an inside pocket.

Dress appropriately. Wear shoes that fit comfortably so that you can move quickly and safely, if necessary. Wear your nametag so patients can be assured you are a valid representative of EvergreenHealth Hospice Services.

Never knock on unmarked doors or on the doors of homes other than those of patients and family/caregivers you are visiting. Never enter a vacant home.

Don't enter if there are any doubts about the safety of entering a home or an apartment building. Leave and call hospice.

If anyone in the house appears to be drunk or under the effects of drugs, leave and call hospice.

If any weapons are present, leave immediately and call hospice.

If a pet is hostile, ask that it be contained, or leave. Let hospice know.

If any of the above situations occur, let a hospice Volunteer Coordinator know and document in your note.

Precautions To Take While Walking

Avoid groups of people lingering on corners or in doorways. Cross the street to avoid them.

Stay near people who are moving about. Walking in lonely, isolated areas may invite attack. Do not take short cuts down alleys, through buildings, or across private property. Avoid narrow or confined spaces.

Carry keys in your hand. This will enable you to get into your car immediately, and you can use them as a method of self-defense. Hold the key ring in the palm of your hand and put one (1) key between each of your four (4) fingers with the sharp ends sticking out. You may want to attach a whistle on your key ring, which can be used to summon help.

Think about your appearance. Your badge will indicate your healthcare purpose to the public.

Walk confidently. Know where you are going. If you don't, go to a store and ask or call for directions.

Self-Defense Measures

If you think you are being followed by someone on foot, cross the street, vary your pace, or change directions. If the person persists, go to a lighted store and call the police.

If you think you are being followed by someone in a car, turn around and proceed in the opposite direction. If the person persists, jot down the car's license number and proceed to the nearest police station or safe station.

If you are being robbed: Size up the situation—think quickly about the wisest response.

Stay alert—take note of the assailant's characteristics so you can give a full description to the police.

Stall for time by talking or fumbling for money—someone may come to your rescue.

Try to get away, if there are people around or open stores nearby—you may be able to run toward them.

Do not be heroic by taking foolish chances—your assailant may become violent. It's better to lose your money, medications, or equipment than your life.

If You Are Being Attacked: Use your natural defenses.

- Make a scene—take your assailant by surprise.
- Jab with your elbow.
- Twist to break free.
- Bite hard.
- Scratch with your fingernails.
- Yell to alert passersby or scare off assailant.
- Swing briefcase/hospice bag at the head of the assailant.
- Bend assailant's fingers back.
- Turn over any meds the assailant wants—don't be a hero

Escalating Behavior: Recognizing behavior is key to avoiding confrontations, diffusing situations, and maintaining your safety as you volunteer. Below are some warning signs that may signal escalating behavior. If you find yourself in a situation that is escalating, leave, call hospice, and let a hospice volunteer coordinator know.

Physical Warning Signs: Pacing, Defensive posture, Fist clenching, Grimacing, Emotional Warning Signs, Disorientation and/or Excitability

Verbal Warning Signs: Angry, loud tone; cursing, Threats, and/or Defensive or hostile reaction to questions

Wheelchair Safety

Before you transport a patient, be sure to gel your hands with sanitizer. Re-gel your hands when you are done.

Ask the patient if it is OK for you to transport them.

Check the wheelchair before you start out to transport the patient for safety including the footrests, arm rests, and weight capacity.

Make sure the footrests work and that they are in the upright position

Make sure the brakes are on before asking the patient to be seated.

Stand behind the chair with the brakes on and brace the chair so the patient can seat themselves easily.

Ask the patient if you can help place their feet in the footrests.

Make sure that the patient's hands and arms are inside the chair and not dangling.

Check for any coats, bags or purses to make sure they don't get caught in the wheels.

Release brakes and grasp handles firmly.

Proceed slowly at a safe pace.

Do not use your cell phone while transporting a patient.

Keep an eye on your patient and the path you are walking at all times.

Watch your path, check for uneven surfaces or any construction. Use extreme caution if you find any of these and move slowly.

Back patients into elevators and down any ramps.

Lock brakes when the patient is ready to get out of the chair. Put foot rests in the upward position. Stand behind the chair and while bracing the chair, let the patient know they can stand up now.

If the patient falls and can't get up, stop immediately and call 9-911 (hospice center) or 911 (in the field). Ask someone near you to call if you are not next to a phone and you are in the field, notify hospice by calling 425-899-1070. Fill out an incident form with a volunteer coordinator as soon as possible.

When you are done, clean the wheelchair with sani-wipes: Wearing your non-latex gloves, wipe down all surfaces on the wheelchair, including the seat, side rails, back, handgrips, brake handles and the anti-theft bar. When done, remove your gloves and gel your hands with sanitizer.

If you are at the hospice center, return the wheelchair to the volunteer reception desk closet nook.

Some people cannot be transported by volunteers (i.e., bariatric, people that have oxygen tanks). If you are at the hospice center, order a Patient Transport.

DocID: 10054
Revision: 9
Status: Official
Department: Compliance and Ethics
Manual(s): Compliance

Policy: Code Of Conduct

1. Background

A. A key element of the EvergreenHealth (EvergreenHealth Kirkland & EvergreenHealth Monroe) Compliance Program is the Code of Conduct. The purpose of the Code of Conduct is to reinforce EvergreenHealth's Mission, Vision and Values, and serve as a guide for moral, ethical and legal behavior.

B. Our Code of Conduct is designed to:

- Communicate EvergreenHealth's commitment to comply with laws, regulations, standards of care, ethical business practices and the basic standards expected in the workplace;
- Ensure that each employee understands their responsibility for keeping in full compliance with these laws and regulations and specifically their responsibility as part of EvergreenHealth's Compliance Program;
- Protect the integrity of clinical decision-making based on patient assessment regardless of compensation arrangements and;
- Provide written guidance regarding how to reduce fraud, waste and abuse.

C. This Code of Conduct and the EvergreenHealth's Compliance Program have the full endorsement of the Board of Commissioners and the management team. It is important that each employee be familiar with the Code of Conduct as it provides an overview of the Compliance Program and the general topics that it covers.

2. Introduction

A. EvergreenHealth recognizes that its employees are key to providing a high-quality healthcare experience for both clinical and nonclinical business activities. It is also recognized that all associated with EvergreenHealth must act in accordance with this Code of Conduct and all other applicable policies, procedures, laws and regulations. Failure to do so can result in serious consequences, up to and including termination. All EvergreenHealth Staff have an affirmative duty to report compliance issues or violations of the Code of Conduct to the Compliance Hot line (888-497-4458), the employee's supervisor or manager, or the Chief Compliance Officer. This requirement includes, but is not limited to, reporting any issue that appears to involve actual or suspected Medicare program noncompliance or potential fraud, waste, or abuse.

B. While this Code of Conduct is designed to provide overall guidance, it does not address every conceivable situation. More specific guidance is often provided in EvergreenHealth's policies and procedures. These policies are periodically reviewed and updated and can be found on Lucidoc, for EvergreenHealth or PolicyTech, for EvergreenHealth Monroe, which serve as EvergreenHealth's document management sites. If there is no specific policy, or if another policy conflicts with this Code of Conduct, this Code of Conduct takes precedent.

C. This Code of Conduct is a "living document" that is updated periodically to respond to changing conditions or regulations. Questions regarding this Code of Conduct, or any compliance issue, can be directed to the employee's immediate supervisor, manager, or to senior management. Issues can also be reported confidentially and anonymously to the Compliance Hot line or directly to the Chief Compliance Officer. For more information about the Compliance Hot line and placing an anonymous call, please refer to the Corporate Compliance Hot line Policy.

D. This Code of Conduct is provided to every employee upon hire and whenever it is modified in a material way. Each employee is responsible for annually reviewing the Code of Conduct and completing an annual attestation stating that he/she agrees to abide by the standards set forth in this Code of Conduct. A record of the attestations is maintained in each employee's personnel record or in the LMS system.

3. Enforcement

Failure to comply with this Code of Conduct or to conduct business in an honest, ethical, and compliant manner can result in civil fines or criminal penalties against EvergreenHealth and/or its employees and/or corrective action by EvergreenHealth, up to and including termination. Supervisors, Managers, and Directors are responsible for ensuring that their employees participate in any mandatory training related to Compliance, and complete the annual Code of Conduct Attestation. Completion of the annual attestation is a condition of employment and failure to comply will result in termination. Compliance with the Code of Conduct is a factor in evaluating the performance of EvergreenHealth employees. (Corrective Action Guidelines)

4. Commitment to Compliance

A. Quality, honesty and integrity are important values to all who are associated with EvergreenHealth. EvergreenHealth is committed to providing quality healthcare and services in full compliance with its mission and organizational values. While laws, regulations and requirements are constantly changing, EvergreenHealth is committed to complying with them. The Compliance Program assists with this process.

B. This Code of Conduct applies to all employees, including temporary and contract employees, as well as volunteers, Medical Staff members, and, when practical, independent contractors. The terms "EvergreenHealth", "we", "you", and "Employees", as used in this document, are meant to refer collectively to employees, Board members, providers, volunteers, students and all other individuals who act as representatives of EvergreenHealth.

C. Violations of the Code of Conduct have serious consequences for all involved and must be addressed.

What is my role in the Compliance Program?

- i. Read and understand the Code of Conduct and other policies and procedures that pertain to your role.
- ii. Remember that all are responsible for helping to keep EvergreenHealth compliant.
- iii. Complete the annual Code of Conduct attestation form.
- iv. Ask questions and report concerns, if a compliance issue is suspected or exists.

5. Selected Elements of the EvergreenHealth Operating System

A. **Mission:** To advance the health of communities we serve through our dedication to high-quality, safe, compassionate, and cost-effective health care.

B. **Purpose:** Working together to enrich the health and well-being of every life we touch.

C. **Vision:** To create an inclusive community health system that is the most trusted source for health care solutions.

D. **Values:** Shared beliefs that define our culture: Accountability, Collaboration, Excellence, Respect, Compassion

E. **Leadership Principles** As leaders at EvergreenHealth, we strive to follow the ten Leadership Principles:

We are the stewards of our culture. How we embrace and live our values and these principles cultivates a consistent and intentional culture of compliance.

We are accountable for achieving exceptional outcomes and for applying the learnings from our successes and failures to help us improve every day.

We are committed to continuous, incremental improvement to eliminate waste, inefficiency, ineffective communication, and variations in our care processes.

We are “teachers and coaches” supporting the professional growth of our staff, and helping our teams achieve their highest potential.

We find opportunities every day to genuinely recognize and celebrate the excellent work of our staff, physicians, and volunteers.

We listen and communicate effectively, always seeking first to understand and then to be understood.

We are consistently responsive and timely to those we serve.

We are inclusive and transparent in our decision making and communications.

We are committed to learning and growing as leaders in the application of these principles.

We role model healthy and rewarding personal lives that are in balance with the demands of our work.

6. Standards Of Excellence

A. Employees have the right to voice concerns and suggestions related to their wages, hours and working conditions. Nothing in this Code is intended to limit employees’ rights to protected concerted activities.

B. Questions about the existence, interpretation or application of any law, regulation, policy or standard should be directed to the person to whom you report or to the Compliance Officer.

C. All of EvergreenHealth’s business affairs must be conducted honestly, fairly and with integrity, all in accordance with federal, state and local laws, professional standards, applicable federally funded healthcare program regulations, and EvergreenHealth’s policies and procedures. Each person subject to this Code of Conduct is expected to perform his or her duties in good faith, in a manner that is reasonably believed to be in the best interest of EvergreenHealth and its patients, and with the same care that a reasonably prudent person in the same position would use in the same or similar circumstances.

7. Patient Care

A. **Emergency Treatment:** EvergreenHealth complies with the Emergency Medical Treatment and Active Labor Act (“EMTALA”) in providing a medical screening exam and necessary stabilization of all patients with an emergency condition regardless of their ability to pay. In an emergency situation or if a patient is in labor, we will not delay the medical screening exam and stabilizing treatment to obtain financial or demographic information. Patients with emergency medical conditions are transferred to other facilities only at the patient’s request or if the patient’s medical needs cannot be met at EvergreenHealth and appropriate care is available at another facility that has agreed to accept the patient. (Patient Transfers to other Healthcare Facilities)

B **Patient Rights:** EvergreenHealth recognizes the personal dignity of all patients and respects their right to participate in decisions regarding medical care and to access and control the use and disclosure of their protected health information (“PHI”) as provided by law. (Patient Rights and Responsibilities and Notice of Privacy Practices)

C. **Patient Health Information:** Patients’ healthcare records are the property of EvergreenHealth and shall be maintained to serve the patient, necessary healthcare providers, the institution and third party payors in accordance with accrediting and regulatory agencies, and applicable law. The information contained in the healthcare record belongs to the patient and must be protected. All patient care information, whether it is electronic, on paper, or oral, must be regarded as confidential and available only to authorized users, such as treating or consulting physicians, employees who are involved in providing treatment, payment processing, or healthcare operations, and to third party payors in order to facilitate reimbursement. Patient information may never be accessed for personal reasons. (Information Security and Privacy Sanctions; Access to Health Information)

D. **Quality of Care and Patient Safety:** EvergreenHealth is committed to providing high quality, evidence-based safe care for its patients, and a safe work environment for employees. Care and services are improved by acting on information received from a variety of sources, including SafeLinQ event reporting, patient feedback, audits and case reviews, data analysis, literature, and best practice information. All at EvergreenHealth strive to meet or exceed regulatory standards with the expectation of individual and collective compliance with the standards.

Each employee is accountable for his/her own performance and practice which complies with EvergreenHealth's standards and expectations, and for identifying and reporting variances and opportunities for improvement. While quality and patient safety activities focus on system and process issues, reckless behavior is addressed when identified.

EvergreenHealth practices transparency by public reporting and sharing of outcome information within EvergreenHealth and with the community.

Employees and Medical Staff members who have concerns about patient safety and/or quality of care are encouraged to report their concerns via SafeLinQ or to the Quality Department. Patients are encouraged to report their concerns to the Patient Relations Department. Concerns may also be reported directly to the Joint Commission/DNV GL or the Department of Health Facility and Service Licensing.

8. Business Practices

A. Anti-Competitive Conduct: EvergreenHealth will not engage in anti competitive conduct that could result in an unreasonable restraint of trade or a substantial lessening of competition. Communications with competitors about matters that could be perceived to have the effect of lessening competition or could be considered as collusion or an attempt to fix prices are not allowed and any such communications that even have the potential for such must take place only with administrative approval and after consultation with legal counsel.

B. Anti-Kickback and Self-Referral (Stark): EvergreenHealth shall not engage in any conduct that may violate anti-kickback and/or self-referral laws. These laws prohibit seeking, accepting, offering to pay, or paying- directly, indirectly, or in a disguised manner- payments in exchange for services or the referral of patients. (Anti-kickback and Self Referral)

C. Documentation, Coding and Billing: EvergreenHealth is committed to ensuring that documentation, coding, billing and submission of claims to Medicare, Medicaid and other third-party payors is appropriate, accurate and in compliance with applicable laws and regulations. This includes billing only for services and care provided and documented, according to medical necessity guidelines. (Billing and Claims Reimbursement)

D. Confidentiality: In addition to patient confidentiality, the operations, activities, business affairs and finances of EvergreenHealth should be kept confidential and discussed or made available only to authorized users for EvergreenHealth's business purposes. (Information Security and Privacy Sanctions). Examples of business information that must be kept confidential, except to the extent the information is already publicly available: Pricing and costs, Acquisitions, divestitures and other strategic relationships, Business and marketing plans, Staffing level plans, Employee and customer lists, and Research and quality data.

E. Credit Balances: EvergreenHealth complies with federal and state laws and regulations governing credit-balance reporting and refunds all over payments in a timely manner.

F. Excluded Business Relationships: Any individual, including employees, commissioners, physicians, vendors, consultants, contract individuals, volunteers or services, and/or other third-parties that have been sanctioned by the Medicare, Medicaid, and/or other federal programs, are excluded from any business or other relationship with any entity of EvergreenHealth. Only upon reinstatement by the governing agency can a business relationship be considered. Sanctions represent a full range of administrative remedies and actions available to the government to deal with questionable, improper, or abusive practices under the Medicare and Medicaid programs. Sanctions result when a healthcare provider violates obligations and requirements governing items and services he or she renders bills for and is paid for on behalf of Medicare or Medicaid beneficiaries. (Recruitment/Transfer/Pre-employment Screening; and Vendor Policy)

G. False Claims Act: EvergreenHealth will not knowingly or intentionally submit false, fraudulent, or misleading claims to any government entity or third-party payor, including, but not limited to, claims for services not rendered, claims for medically-unnecessary services, claims which characterize the service differently than the service actually rendered, claims with inaccurate diagnosis or patient identification data, or claims which do not otherwise comply with applicable program or contractual requirements (Corporate Compliance Program Auditing and Monitoring). EvergreenHealth will not make false representations to any person or entity in order to gain or retain participation in a program or to obtain payment or excessive payment for any service. (False Claims Act)

H. Financial Inducements/Gifts: EvergreenHealth shall not offer or accept any financial inducement, gift, payoff, kickback, or bribe intended to induce, influence, or reward favorable decisions of any government personnel or representative, any customer, patient, contractor or vendor in a commercial transaction or any person in a position to benefit EvergreenHealth or the employee in any way. (Gifts- Acceptance and Giving).

EvergreenHealth limits the gifts (other than cash or cash equivalents) to patients to be \$15 or less per occurrence and must not exceed \$75 in a given calendar year.

The Foundation coordinates all gift acceptance activities and donor records on behalf of all fundraising activities for the District. (Gift Acceptance and Fund Disbursement)

Appropriate and legal commissions, rebates, discounts and allowances are customary and acceptable business inducements provided that they are approved by Administration and that they do not constitute illegal or unethical payments. Any such payments must be reasonable in value, competitively-justified, properly documented, and made to the business entity to which the original agreement or invoice was made or issued. Such payments should not be made to individual employees or agents of business entities. Commission, rebates, discounts and allowances shall be accurately reflected on EvergreenHealth's annual Cost Report.

I. Conflict of Interest: In order to perform their duties with honesty and fairness and in the best interest of EvergreenHealth, all employees must avoid conflicts of interest in their employment. A conflict of interest or the appearance of a conflict of interest may exist when employees, by reason of their position, authority or knowledge, allow or cause themselves, friends and relatives or anyone with personal ties to benefit directly or indirectly by their actions on behalf of the organization, or allow or cause the organization to be adversely affected in any way. Potential conflicts could be serving on an outside board, having ownership in a company that EvergreenHealth conducts business with or working outside of EvergreenHealth.

Conflicts also may arise in other ways. If an employee has any doubt or question about any of their proposed activities, guidance or advice should be obtained from their supervisor, the Compliance Officer or Human Resources (Conflicts of Interest, and Conflicts of Interest in Research). Any employees who have actual or potential conflict of interests must timely complete the Conflict of Interest Attestation & Disclosure Statement.

J. Financial Reporting: All financial reports, accounting reports, research reports, expense accounts, time sheets and other documents must accurately and clearly represent the relevant facts of true nature of a transaction. Improper or fraudulent accounting, documentation or financial reporting is contrary to EvergreenHealth policy and a violation of applicable laws. Sufficient and competent evidential material or documentation shall support all cost reports.

K. Fraud, Waste and Abuse (FWA): EvergreenHealth is committed to preventing, detecting and correcting fraud, waste and abuse related to healthcare benefits, regardless of whether those benefits are paid by the government, a commercial health plan, or an employer. All employees and anyone involved in Medicaid or Medicare (or other federal benefits program) must receive FWA training, both at hire and annually, and successfully complete any required examination. Such training includes high-level information regarding the False Claims Act (see Section H.7., above), Health Care Fraud Statute, Anti-Kickback and Stark Statutes (see Section H.2., above), Exclusion from all federal health care programs (see Section H.6., above), and the Health Insurance Portability and Accountability Act. Employees are trained to:

Look for suspicious activity

Conduct themselves in an ethical manner

Ensure accurate and timely data and billing

Know and follow FWA policies and procedures

Standards of conduct

Laws

Regulations

CMS guidance

Verify all received information.

In addition, any person that is aware of or suspects Medicare program noncompliance or potential healthcare fraud, waste or abuse is responsible for reporting it to the Compliance Officer. Please see Section I. 4.

L. Investigations: EvergreenHealth is committed to investigate all reported concerns promptly and confidentially to the extent possible. The General Counsel or the Chief Compliance Officer, in collaboration with Human Resources, when applicable, coordinates any findings from internal investigations and promptly recommends corrective action or changes that need to be made, so that all investigations will be closed in a timely manner. All employees are expected to cooperate with internal and external investigation efforts. Status and updates are available for investigations resulting from a call to our Compliance Hot line by calling its telephone number and providing the Report Number and PIN given at the time of the original call.

M. Duty to Report and Cooperate in Investigations: Each member of EvergreenHealth's workforce has an affirmative duty to report compliance issues. This requirement includes, but is not limited to, reporting any issue that appears to involve actual or suspected Medicare program noncompliance or potential fraud, waste, or abuse. All reported issues are investigated and, if appropriate, addressed and corrected. If, upon investigation, the issue is found to be a violation related to Medicare program noncompliance or fraud, waste, or abuse, Compliance will report it to appropriate governmental agencies, including Medicare Plan Sponsors. EvergreenHealth cannot and will not retaliate or discriminate against an employee or other individual who, acting in good faith, reports a violation of the Code of Conduct, EvergreenHealth policy, or law. However, this does not protect reporters from appropriate disciplinary action regarding their own performance or conduct. Any individual who deliberately makes a false accusation with the intent of harming another individual will be subject to disciplinary action. In addition, each person to whom this Code of Conduct applies has a duty to cooperate in compliance investigations. (See also Response to Subpoenas below). A good faith report is one made about something that the reporter believes to be true and believes is a violation of the Code of Conduct, another EvergreenHealth policy, or law. A report that is made maliciously or frivolously is not in good faith.

N. Equal Opportunity Employment: EvergreenHealth is an equal opportunity employer. As such, EvergreenHealth offers equal employment opportunity without regard to age, race, color, creed, ethnicity, religion, national origin, marital status, sex, sexual orientation, gender, gender identity or expression, disability, veteran or military status, the need to use a trained guide dog or service animal, or on any other basis prohibited by federal, state, or local law. Equal opportunity shall pertain to hiring and firing; compensation, assignment or classification of employee; transfer, promotion, layoff or recall; job advertisements; recruitment; testing; use of company facilities; training and apprenticeship programs; fringe benefits; pay; retirement plans; disability leave; or other terms and conditions of employment. Unlawful discrimination will not be tolerated. (Equal Employment Opportunity; and Equal Opportunity Employment)

O. Research: All research, including externally funded projects, conducted by EvergreenHealth employees, or with the use of EvergreenHealth resources or facilities, must be approved by the Department of Research and comply with relevant policies and guidelines. (Research at EvergreenHealth)

9. Workplace conduct and employment practices

A. Harassment and Workplace Violence: Physical conditions are only one component of the work environment. EvergreenHealth must also be free of any kind of discrimination and harassment. Actions, words, jokes, or comments based on, reflecting, or referring to an individual's age, race, color, creed, ethnicity, religion, national origin, marital status, sex, sexual orientation, gender, gender identity or expression, disability, veteran or military status, the need to use a trained guide dog or service animal, or on any other basis prohibited by federal, state, or local law will not be tolerated. A prompt investigation will be conducted, and appropriate corrective action will be taken where it is warranted.

Sexual harassment is a form of misconduct that undermines the integrity of the employment relationship. No person should be subject to unsolicited and unwelcome sexual overture or conduct, either verbal or physical. Sexual harassment does not refer to occasional compliments of a socially acceptable nature. It refers to behavior that is not welcome, that is personally offensive,

which undermines morale, and therefore interferes with work effectiveness.

Acts of sexual harassment committed by any individual associated with EvergreenHealth is specifically prohibited as unlawful and against EvergreenHealth policy. Any individual who has reason to believe that he or she is the victim of harassment or discrimination should promptly report the facts of the incident to his or her direct supervisor, a Human Resources Business Partner or Human Resources leader or by contacting the Compliance Hot line at (888) 497-4458. (Harassment Free Work Environment; Workplace Violence Prevention Program)

10. Personal Relationships between Employees in the Workplace

A. Friendships of a non-romantic nature sometimes develop between EvergreenHealth employees in the workplace. EvergreenHealth recognizes the development and existence of such friendships and personal relationships provided that they do not and will not interfere with the work performance of either individual or with the effective functioning, safety and security of the workplace.

B. Personal relationships that include romantic and/or sexually intimate relations where the conditions described below do not apply (e.g., employees with the same level of responsibility) are to be conducted with consideration for professional responsibilities and standards and with respect to concerns about favoritism, bias, ethics and conflict of interest.

C. Romantic or sexually intimate relationships between employees where one participant has the actual or practical authority to hire, supervise, evaluate, promote/demote, discipline or discharge the other employee, or to make meaningful recommendations concerning compensation, benefits, work role and assignment or other terms and conditions of employment for another participant's conditions of employment (e.g., management and subordinate) are inappropriate and prohibited ("Prohibited Relationship"). These relationships, even if consensual, may result in conflict, impact the professional standard we uphold or compromise equity or safety of either employee or others. Even the appearance of such relationships can be problematic.

D. Any Prohibited Relationship must be promptly reported by the participants to Human Resources. In addition, any other person knowing of an actual or suspected Prohibited Relationship must report it to the Chief Human Resources Officer or anonymously to the Compliance Hotline at (888) 497-4458.

E. If a Prohibited Relationship is made known to EvergreenHealth, the circumstances will be reviewed to determine whether, in light of all available information, one or more participants should be placed on a temporary leave of absence, moved to another position, or separated from employment at EvergreenHealth.

11. Health and Safety

A. **All are responsible for making EvergreenHealth a healthy, safe, and caring work environment.** Each person must exercise good judgment with regard to the environmental aspects of the use of buildings, equipment, and supplies, including complying with EvergreenHealth's no smoking policy and proper discharge and disposal of any hazardous materials used and/or generated in performance of one's duties. (Smoke and Tobacco Free Environment, HR-WS 206; Hazard Communication Program)

B. **Infection control policies and procedures have been developed for the safety of all.** Failure to follow prescribed policies and procedures could place anyone exposed at risk. EvergreenHealth is committed to meeting or exceeding all industry standards established for the control of infectious diseases and adherence to those standards is an essential job responsibility. (Infection Control Operational Guidelines; Hand Hygiene)

C. **Inspection and testing of all equipment is also essential.** All operators of equipment are expected to be aware of and exercise this responsibility as one's duties may require. Equipment inspections and testing must be done in a timely manner and in accordance with the manufacturer's maintenance guidelines. (Minimizing Risks)

D. **Information Technology:** EvergreenHealth has established policies that govern the appropriate use of information technology resources, including personal use of the internet and EvergreenHealth email systems, security mechanisms, and downloading of software. (Appropriate Use of Computing Resources)

What can each person do to help protect EvergreenHealth information?

- i. Never share your computer passwords with anyone for any reason
- ii. Lock or restart your computer work stations before leaving them, even for a short time
- iii. Don't open email attachments, click on links, or fill out forms that are suspicious or come from someone not known
- iv. Secure mobile computing devices, such as laptops, cell phones, PDAs, and thumb drives
- v. Never discuss patients or patient information in unsecured areas

13. Intellectual Property

A. Employees will not disclose or misuse any confidential or proprietary information or trade secrets that they have access to during the course of their employment with EvergreenHealth and even after their employment at EvergreenHealth ends.

B. Employees may, during the course of their work at EvergreenHealth, develop or be part of a team that develops a new invention, published work, software program or other type of intellectual property. If an employee develops intellectual property within the time and scope of their work at EvergreenHealth, because EvergreenHealth pays their compensation and provides all facilities and resources for their work, EvergreenHealth owns the rights to the invention. (Intellectual Property at Evergreen)

14. Political Activity

As a public hospital district, EvergreenHealth cannot engage in political activity that supports or opposes a candidate for elective office or a ballot measure, except in certain limited situations. No district employee or volunteer may use any District resources or property to support or oppose any candidate for office or any ballot measure. Any employee learning of another's such use has a duty to report it. (See Section I.4., above.) (Political Campaigns and Elections)

15. What Kind Of Political Activity May District Employees Participate In?

District employees may participate in political activities or organizations on their own time, so long as:

- I. You do not use District resources, including its computer and email system;
- II. Your participation does not create a conflict of interest; and
- III. You do so as a private citizen and do not imply endorsement of the activity or organization by the District.

16. Protection of Assets

A. EvergreenHealth will make available to employees assets and equipment necessary to conduct EvergreenHealth business, including such items as computer hardware and software, billing and medical records (hard copy and/or in electronic format), fax machines, office supplies, copy machines and various types of medical equipment. Employees should use these assets in a prudent and effective manner. EvergreenHealth property should not be used for personal reasons or be removed from EvergreenHealth facilities without appropriate approval. This includes, but is not limited to, using medications intended for patients, whether prescription or over-the-counter (such as ibuprofen and acetaminophen), for personal use or for use by patients outside of EvergreenHealth. (Medications for personal use are available for self-purchase from the EvergreenHealth or other retail pharmacy.)

B. Employees are required to report time and attendance accurately. (Time cards)

C. Employees are expected to adhere to EvergreenHealth's policies regarding Record Management, Retention, and Destruction. (Records Disposition Management; Records Retention)

17. Response to Subpoenas

EvergreenHealth has a policy about responding to a subpoena or search warrant. In general, employees should not accept service of a subpoena and should contact Administration immediately. (Response to Subpoenas and Search Warrants; Legal Investigations; and Court Orders)

18. Substance Abuse

A. EvergreenHealth is a drug-free environment. Employees must report to work on time and free of any drug or alcohol that can impair their job performance or risk the health and safety of patients, other employees or guests.

Unlawful manufacture, distribution, dispensation, possession or use of drugs and/or alcohol is prohibited on EvergreenHealth grounds or during work time and will result in disciplinary action, up to and including dismissal.

B. EvergreenHealth recognizes and acknowledges drug and/or alcohol dependency as a major health problem and encourages employees to seek rehabilitation referral through the EvergreenHealth Employee Assistance Program and to utilize health insurance benefits to provide help with dependency. All referrals are confidential.

C. If an employee is convicted of a drug-related crime occurring at the workplace, he or she must notify Human Resources within five days of the conviction. (Substance Abuse)

19. Additional Standards

EvergreenHealth has adopted a number of other organization-wide policies and procedures. Employees may obtain copies from the Lucidoc/PolicyTech document repository.

There may also be additional standards and policies that are applicable to particular departments and copies may be obtained from supervisors, managers, or directors in those departments.

20. Contact Information

Chief Compliance & Internal Audit Officer, Kirkland:
(425) 899-2018

Compliance Officer, Monroe:
(360) 794-1403

Anonymous, 24-hour, Compliance Hotline:
(888) 497-4458

www.alertline.com

Compliance@evergreenhealth.com