

# 3 • Opportunities at the end of life

## The art of being a healing presence

By Gary Pasternak, MD, Mission Hospice Associate Medical Director

1. When you're a healing presence, you're an artist. Healing is more art than science, and it takes practice.
2. Being present is simple, but that doesn't mean it's easy. Quieting the mind's noise to hear another takes practice and discipline.
3. Healing is about something much larger than curing. Healing is to make whole.
4. As you move toward being a healing presence, there is only one place to begin – with yourself. Calibrate your instrument by being self-aware, experiencing self-compassion, acknowledging judgments and biases, being open and curious about the workings of our own hearts and minds, and honoring and learning from imperfections.
5. It helps to prepare a space if you're to be a healing presence. Clear the physical and psychic space and be mindful of the energy you bring. Consider what helps you maintain an aura of calmness and equanimity.
6. The most important space you prepare is not around you but within you. Prepare yourself: centering, grounding, touching into your intention, prayer mindfulness, silence, letting go of outcomes. Bring yourself with wholeheartedness.
7. The other person is your equal in every way that matters. Hold the other with unconditional positive regard; noticing our biases and judgments and how they separate us from the other. I could be that person. Honor common humanity.
8. Your healing presence can take many forms. Every encounter is improvisational. Who knows what will serve? Being in the moment and being yourself. Being more than your role. Many possible tools but often listening, being receptive and present in your body, talking, holding, serving in myriad ways.
9. One of the most powerful things you can do for someone as a healing presence is simply to believe – having faith or trust that healing can take place, holding a vision of wholeness, touching in with your intention to relieve suffering. Remember times when you've experienced deep healing.
10. A healing presence is most effective when it is least active. Less is more. Helping is the sunny side of control. Resist the temptation to fix or give advice.
11. Healing presence involves being connected while maintaining separateness. Healing evolves from relationship-centered care. Remain wholeheartedly objective (not detached or dispassionate). Don't get swallowed up in sympathy, but practice empathy.
12. You cannot be a healing presence entirely on your own. You need support and nurture. Do what keeps you healthy and supports body, mind, and soul. It takes a village. Share your joys and sorrows.

13. Being a healing presence can bring considerable joy as well as its share of discomfort. Don't push anything away. Lean into painful or troubling situations. Don't ignore the elephant in the room. Compassion can transform suffering into healing. Allow the waves of joy and sadness to come and go.
14. As a healing presence, you won't receive as much as you give. You're likely to receive even more. The dying are our teachers. Fundamentally, there is no separation between giver and receiver. Equitable reciprocity. There are many gifts of this work.
15. A healing presence is filled with sacredness. What is your sense of the divine or spiritual aspects of being a healing presence? Be present for the "full catastrophe."

**Be present with willingness, simplicity, and gratitude.**

**Keep a strong back and a soft front.**

***“Being part of the Mission Hospice team feels like coming home. There is no greater feeling than knowing you play an important role in something far greater than yourself.”***

*– Mary Santana  
Chief Clinical Officer*

## Why we love this work

By Gabrielle Jimenez, LVN, CHPLN

I went to nursing school in my late forties specifically to become a hospice nurse. I was caring for a friend of mine who was dying and felt a sense of peace at his bedside, as though it were a chair that had been saved for me until I finally found it. This work is intimate, private, personal, powerful, and lovely. No matter how many last breaths I witness, it always feels like the first. It is such an honor to be present at the bedside for someone who is dying, as well as for those who are saying goodbye.

Each first hello, and last goodbye is a reminder to me that life is fragile, and our time here is unpredictable. I want to be the last kind word someone hears, I want to be the kind of person that makes a difference for others, that inspires them, that reduces their fears, and that reminds them they are not alone. I appreciate life in a way I never have before, and I savor it all... I am pleased when I can start seeing someone early in their diagnosis, because it allows me to get to know them, find out what they want and what their wishes are, and how they want to be cared for as they start to decline. If I am lucky, I meet their families and hear their stories.

Human beings deserve to be cared for well when they are dying; to be heard, to have their thoughts and wishes, and even their fears validated.

I put their needs first. I focus on listening, because I think all human beings deserve to be heard, but also because if we listen, if we lean in and truly hear what people need, we can honor their wishes and care for them well. Each person I meet along my path, teaches me about life, love, kindness, and compassion, all of which are beautiful gems I keep safely tucked inside me.

Meeting them where they are, not where I want them to be, is something I didn't quite understand early on. This was something I learned after realizing their experience is not about me. Meeting someone where they are means putting aside our wants for them, whether those wants are in service to them or not and endeavoring to understand where they are in their journey... not where you think they should be. It begins by listening without judgment, asking questions openly and honestly, and above all recognizing that they are human.

It is so easy to project what we think someone else needs, and to push our own wants and wishes onto them, but what I think is more respectful, is truly meeting them where they are and honoring their needs.

I have learned that I don't always have to be there for the last breath, as long as I make the time that I am there valuable for the patient and their family, and that has to be enough for me. When you work in end-of-life care you are constantly caught between feeling sad that they are gone, but happy they let go. This is an emotional seesaw we are all continuously learning to find balance on. Do we get attached? Sometimes, yes. I think that is why self-care is that much more important for us to practice. If we stop having an emotional reaction to the end of a life, and the ache people feel when they say goodbye, we should stop doing this work.

When we are at the bedside of someone who is dying, our presence is not always just about them... it is also for those who are preparing to say goodbye. The partner of the person in the bed has two roles – partner and caregiver – and the lines between them can become blurry. They need our support the minute they take on that second role. And our role (because we have one

too) is to reach out and offer them a break, or to make a meal, or pick up groceries. There are so many things we can do for them that won't take up too much time or money. Imagine the difference you can make for them.

The moment you start providing care for another human being, a bond is created, and you become emotionally connected and tied to this person. All the time you spend with them, caring for them, and focusing on their needs, the more you forget your own. YOU need care too and it is essential that you find a way to practice self-care and honor the needs of your own body. And when that time comes when you have to say goodbye to them, this loss will be big and your grief will be real; you cannot do this alone. Please reach out to someone; let them know you need support.

For a long time, I think I felt like if I admitted how hard it was, or how fragile I was feeling, it would mean I was not up to the task of taking on this job, and that perhaps I was too weak to do it. But that is not the case at all, I am fragile, but I am not weak. Weak would be not admitting you have tough days, weak would be not honoring what your body says to you, and weak would be not accepting that you are a human being doing a job that many could never even attempt, which is hard, and sad, and can take its toll... but it is also beautiful and fills my soul, and I wouldn't have it any other way.

At the end of every single day, I ask myself, "what did I do well, what could I have done better, and what did I learn." My reason for this is to keep finding the balance between the blurry lines of end-of-life care, to accept my emotional reaction as the reminder of how truly precious life is, and to always stay focused on what matters most of all, which is that a human being was cared for well, and that is always my goal. Death has taught me to pay closer attention to life. Each last breath that I am present for shocks me because I realize the finality of it, as well as how truly fragile we are as humans, and how blessed we are to have breath, and life.

When you work in this field and experience your own personal losses, you find your-self in between standing so still you are afraid to move and moving forward swiftly, as though it never happened. Neither are healthy. I have found that facing all my feelings head on, really feeling them, honoring them, and wiping the sticky off them, helps. I call it "sticky," because that is what grief feels like to me... like it's stuck to me, which then becomes stuck to everything I touch. To work in a field where you have to be strong enough to witness difficult moments, and comfort others who are trying to navigate them, you have to take care of yourself and find a self-care routine that can fit nicely into your daily life. Journaling, blogging, meditation, yoga, running, walking, hiking, cooking, time with family and time with friends... all of this can center and ground you. This work is beautiful, but it cannot be everything you are or do.

I cry easily and often, and there was a time early on that I felt I needed to hold it in. I spoke to one of the hospice doctors about it, and he looked right at me, into my eyes, and he told me to feel whatever I was feeling. He gave me permission to ache for this loss, which was mine too. He told me that to be able to do this work well, we have to remember that we are bearing witness to the end of a life. He said that if I should ever stop feeling a sense of sadness witnessing a last goodbye, only then should I be concerned about whether I am capable of continuing to do this work. Their experience is not about us and projecting what we think they might need is not helpful. If we meet them where they are, if we truly listen to what they want or need, imagine how that makes them feel. When someone is nearing the end of their life, what I want most of all is for them to feel as though they were cared for well.

One thing it is always important to remember, is that THIS IS NOT ABOUT US. We should not project what we think someone else needs or wants, whether they have a voice or not. It is not for us to say he should or should not be alone when he dies..... I was reminded that it does not matter who someone prays to, kisses, votes for, or how they live ... this is their choice, and it is not for us to judge, insult, ridicule or verbalize any unkind words or energies in their direction.

I am often asked why someone is taking so long to let go, or an even harder question, is why do they have to die? What I have come to realize is that there is no real answer to the why, and there is nothing I can possibly say that would or could change the circumstances of everything that was happening at the time the questions are being asked. Life happens, and then death happens and in between is the space where memories are made, so it reminds us to make the very best of that time. Sometimes we are reminded too late. And when a diagnosis is given, or a life is cut short, the questions we need to ask are, did we live our life well, did we make lasting memories, do the people in our lives know just how loved they are?

For me, at the end of the day, what matters most... is that all human beings are cared for well when they are dying, despite their choices, their lifestyle or anything else that we might not support, agree with, or understand.

I found this quote by Colin Powell, which I believe says it all:

“Don’t just show kindness in passing or to be courteous. Show it in depth, show it with passion, and expect nothing in return. Kindness is not just about being nice; it’s about recognizing another human being who deserves care and respect.”

As a hospice volunteer, you need to know what a difference you will bring to the life of someone who is dying. When you are at the bedside, you offer peace and you offer trust, and in some cases more so than anyone else in their lives. I have witnessed many times the patient sharing things they had never told anyone else, which is usually about their fears and worries about death and dying. Sometimes, patients are afraid to be open with their loved ones, they don’t want to add to the pain they are already going through, that is why this role is so important, your role is so important. The advice I gift most often, is to listen, not to fix, not to share your thoughts or your opinions, but to hear them and to validate their words. By doing this, you are building trust. And that is a beautiful gift.

When you meet someone who is dying, always remember what this means to them, and what they might be going through. Time suddenly takes on a whole new meaning when yours has been cut short, and it is at this time when you realize you have wasted a lot of time. There might be regret, anger, guilt, sadness, and pain, which can be physical but is often mental or spiritual as well. There is a lot that needs to be worked through before those last breaths are taken, and your role might just be the safe place for them to share.

Being present for someone who is dying, is an honor, one that should never be taken lightly or for granted. When you first meet them, try not to ask them how they are – we know how they are. Instead, let them know you are pleased to meet them, and that you are there for them in whatever way brings them the most comfort. At the time of that first visit, they may not know what they want or need, they might not know what a gift you are to them, so this is your opportunity to start building that trust. Lean in, and simply say, “it is an honor to meet you.” And let the conversation go from there. You are going to make a difference in their life.