

Working with the Pain of Separation

A Guide for Caring and Mourning at a distance



By Jeanne Denney

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World over, people are finding themselves suddenly separated from sick or dying loved ones who they can't touch or speak to in normal ways while they are ill. If death comes, they may not be able to travel to a funeral, mourn with others, or feel the deep consolation of hugs, kisses and tangible presence. The pain of these separations is profound and visceral. Technology may be offered as a solution, but it is not always available, nor is it enough. We must find other ways to connect with people in need or who have died.

Fortunately, there are means even beyond Zoom and FaceTime. Here is what the dying and those in grief have taught me about presence, communication, and what we can do.

In 2005 I was both a graduate student studying Transpersonal and Somatic Psychology, and a hospice worker with a lot of questions. I was assigned mainly to nursing homes and to patients who were no longer verbal. Rather than avoid their silence, I became fascinated by the problem of what hospice work might mean for someone who could no longer talk. I sought a way to let them teach me. Some of my questions were: "Where are you?" "How can I find a way to find you?" "What do you need?" and "How can I help?" It led to a student

research project which was, admittedly not high academic science, but also groundbreaking as I used biofeedback to get some answers to my questions. I have used this work to teach students how to be responsive companions to the non-communicative. I have used it to help distressed family members trust their instincts and stay present for their silent partners. I have learned that silent presence can be helpful to both patients and their loved ones.

Fifteen years later we are in the middle of a worldwide pandemic. A highly contagious disease is affecting vast numbers of patients who must be separated from family, often very suddenly. Patients and their families both are finding themselves in "non-communicative states". I recognize their pain. The situation is more similar than different from what I witnessed with comatose patients.

Perhaps nowhere do we feel more isolated and alone than an ICU. Even in ordinary times our animal mind and body feels homeless there, far from all that we have known and everyone who we love. Now patients have the added challenge of being cared for by highly stressed people in hazmat gear. This pain is not only felt by patients. The people who love them have lost their role in care: the opportunity to offer touch, comfort, or speak what is in their hearts. If death occurs, the pain may continue in regret. Opportunities to unite as a community

for support and resolution are mainly denied. These are the facts of our moment.

After reading all of this, please, take a moment to notice your body. Breathe. Yes, this is happening. Yes, all of the ways we are used to attending to ourselves and others around death have changed for now. But it is not true that there is nothing we can do. We can still find ways to care and show love, even at a distance. We have to craft our care from a new playbook. My project, as well as being with many dying and grieving people, taught me something about this new playbook. It taught me that connection is possible. I am happy to share a few things I learned and make a few suggestions for navigating our present reality.

Seven things to bear in mind

1. The consciousness of very ill and dying people is different than our consciousness. They can be highly sensitive and open. That is in the plus column.

Dying is usually not sudden. It is a process. This process changes the body, but also the mind. In dying, we retreat to deep interiority for at least a time before death. This change in consciousness may alarm family, but it is not random and it is not as if dying people are nowhere when they stop talking, or are suddenly

just "gone". In their process they become more and more sensitive to others by the moment. That fine sensitivity helps them perceive things. It often makes them a little psychic, or able to know and feel things they might not have noticed in ordinary life. Generally, they are very actively involved with their own inner experiences, and the changes occurring in their own energy system. Those changes usually involve work to resolve relationships. In this work, they seem to search for those they love in order to resolve or complete things. Their search is not just in the "here and now", it extends into time and space in new ways. This change is useful.

2. "Presence" for ill or dying patients can often be felt immediately from a distance. Maybe even a far distance.

Illness and death are full of synchronous communication between loved ones. One thing that you learn early in hospice work is how many incredible things happen between people in relationship, even at long distances. To give two personal examples, I felt an inexplicably urgent desire to call my father the moment before he died just to tell him I loved him. Years earlier I felt my mother's heart attack at the exact moment she was having it, even though I did not consciously know about it until the next day. My parents lived 3000 miles away.

I won't tell you a thousand stories or try to prove this. I will just submit that it is so. Patients may feel very different or more intense things when people are close, but presence and communication is not *only* a function of being physically present. Love and intention to "be with" have a way of traveling. My advice? Act as if it is so.

3. The dying seem to be sensitive to our intentions and the content of our thoughts; the very ill may be too. Though they may enjoy hearing our physical voices, they may also be able to "hear" and "know" in other ways.

In my project there were multiple stunning non-coincidences. They strongly implied this: dying and non-verbal people can often not only sense who is with them immediately and respond differently to people they know, they also seem to respond to the content of thoughts, prayers and intentions. Astonished? This has been borne out by more sophisticated and better funded research than mine. But my patients seemed able to discern their caregivers and have distinct relationships with each one. They were overwhelmingly more responsive to family members and sometimes patients responded to things that we sitters were just thinking or saying silently!

4. Physical touch may comfort us, but it can be overwhelming to someone near death.

A clear finding of my project was that physical touch of a dying person evokes responses in them that resemble those of sudden shock or fear, at least initially.

Familiar touch and voice may surely be welcome from a loved one, but can also easily overwhelm. Even very subtle touch is a very big deal to the body of a person who is comatose, ill or dying. So our concern about not being there in the flesh to touch might be relaxed just a little. As one colleague said it, "for the dying, presence itself is touch". In distance situations we are challenged to learn to touch differently.

5. Even when patients don't seem to be "there" (they are comatose, sedated, or sleeping), they can often be "found" or seen in our mind's eye with eyes closed, in our heart or sometimes we can sense them viscerally, even at a distance. Finding and holding them probably helps. A lot.

I remember something a patient dying alone in a nursing home said to me once. "You don't know what it means to know that someone out there knows I am here." Wow. Huge lesson. My awareness, my willingness to think of her, to feel some of her loneliness, to feel regret when I couldn't go, was felt by her. It made all the difference to her, even when I wasn't there.

Over the years I also found that if I became mindful (or meditated) I could get impressions of people from a distance just by checking in on them with my “mind’s eye” as mentioned above. Other people might use different senses to “know” and connect. Everyone has some ability to do this, or can learn it. The fact is, we are fundamentally connected creatures. Think of how amazing our cell phones are at sending very precise messages through space. We are even more interconnected than that, we just have to learn to recognize and use our capacities.

6. Thoughts, prayers and meditative presence help. Even at a distance.

People have prayed and meditated for the ill and dying at bedside for millennia, in many cultures and across the globe. Anecdotal experiences abound about these practices at bedside. Dying people report that these practices are comforting and give them peace. I won't try to prove it. But even my graduate study provided evidence of this, as patients’ heart rate variability responded positively 6 out of 6 times when silent prayer or meditative presence was offered them by sitters. It isn’t hard to conclude that we benefit others and ourselves with loving focus and mindfulness. Especially others that we are close to.

7. Time is malleable and the dead are very forgiving. That might allow us to think creatively about healing when we can't have things the way we wanted it.

There is something powerful about being with someone through death. It is singularly powerful to be with a person who has just died and offer care for their beloved body, gathering with others to grieve. There is no substitute for this. Yet in our current reality people can't travel or gather at this time. Services are delayed. Mortuaries and cemeteries in some places are overwhelmed. Our plans may have to suddenly change. A memorial may have to happen in the distant future. This surely adds grief to grief. But it may help us to remember that time is especially malleable around the death. The same processes can expand into weeks or contract into moments. They are still the same processes, no less worthy.

Further, when people feel the presence of people who have recently died (yes some people do experience this), the dead rarely come back to say anything but that they are just fine, and that what you are worrying about is no big deal. Please don't. Maybe we are challenged at this time to be flexible, and allow this reality to be *part* of the uniqueness of their particular death. A part of their story we will understand in time.

So...might these ideas help us to be effective? I think so. There are some things we really can do that help.

What loved ones can do

First, if a loved one is isolated and seriously ill, you will need time to grieve, both because you can't be there and because this is not a reality that anyone wanted. It may have happened very quickly. You may be separated by many miles. Try not to get too busy. Make time to feel this.

When you can, inventory what you would want to say and do if you WERE at your loved one's bedside. Then set up a space in your home or outside to be your "sitting at a distance" place. Maybe you can place their picture there. Go there when you wish you could be with them. Sit. Imagine making a linkage between that place and their bedside. Try to center and bring them to mind with as much loving compassion as you can, just as a hospital visit. You may feel things or even see images of them in your "mind's eye". Some people do. Let yourself be open to that. You can even make a few notes of your experiences to share with them later.

When and if you feel that you might, just might, have a sense of them, say what you wish you could say out loud or in silence. Give encouragement. Shower them with affection. Play the soothing music you would have brought. Bring flowers to this corner. Tell a joke. Light a candle. Write them a letter. Ring a bell.

Love powered by mindfulness at a distance can still be very much felt, especially by people who are ill, and who we are connected to. Behave as if this is so.

Complain about something as if you were in the kitchen together. Sing them a song. If you have regrets, speak apologies. Hold your hands in your lap as if you could cradle them in it. Hold them in your heart. You get the idea. If you make this space for sacred communication, I am willing to bet that you will know what to do.

Of course you can try to get medical staff to give actual, audible messages, hold phones and read notes to them. They may or may not be able to. But don't be discouraged if this doesn't happen. Empower *yourself* to communicate. Love powered by mindfulness at a distance can still be very much felt, especially by people who are ill, and who we are connected to. Behave as if this was so. Behave as if your heart was a cell phone calling theirs. It is something like that.

What you can do as a patient if you are not too ill

If you are sick from coronavirus but not hospitalized, you may worry in the wee hours about what will happen to you. Remember, it is very unlikely that you will ever be sedated and ventilated, or even die. But yes, there is a chance. And if that were to happen, there is probably enough time between now and then to

Ask for what you might need from others. Affirm your love.

Say your apologies, forgive where you can. Speak your thanks for what they have given you.

communicate with people you love. Put your worry time to good use. Consider what you need to say to the people you care about as if you will be separated during your illness. Then use your time to speak it. Make the phone calls you

can make. You can acknowledge what no one wants to say: “We could be separated if I get very ill. It might be sudden. I want you to know what is on my mind”. Ask for what you might need from them. Affirm your love. Say your apologies, forgive where you can. Speak your thanks for what they have given you.

I know this is very hard work. We hope that this all never happens. But trust me, this “behave as if” work never hurts a relationship! You can also talk about something else important: “How will we communicate if ordinary communication is impossible?” If you are both open to it, agree on how you will reach out to each other non-verbally in thoughts, prayers and meditation. You can agree that you will at least experiment. It will help.

What Medical Professionals can do

Medical professionals in this moment are being heroic on every possible level. I have no desire to add any “to-do’s” to your plate if you are one! But sometimes opportunities to help arise in strange moments for medical folks. The people who ARE present can really help if they are aware. It will require changing your idea of care just a little. Can you relay a message from someone who calls? Can you read a letter to someone in ICU? Can you reassure them that their family is calling (if they are) and caring. Yes, all of this even if they are sedated. If someone is dying alone with distant family, can you just make a note or two to tell the family something about their death, or about the patient before they died? Can you relay anything that may have been said by the patient, no matter how small, or remember their expressions? All of these things would have been

meaningful to the family if they had been there. You are giving them pieces that may help them make the story of the death of their loved one.

And if there is no family that is calling? Can you be a compassionate witness to the struggle of a person in fear? You are in it with them. YOUR thoughts and prayers really do change things for patients and families. You will be their hospice worker. Can you see them as human, or share from your own human experience?

And what if your loved one dies?

We will be limited in how we can mourn while we are in a pandemic. Our customs will be changed. But one thing we can do no matter where we are is create a ritual of honoring in our own homes or in Nature. It is even more powerful to do this simultaneously with others as they do their ritual in their home places. For now. After, maybe you can convene a zoom meeting to raise a glass together. For now. We can offer each other support, and offer the dead prayers. For now. Finally, we can begin to plan the memorial we will have when we do convene together. Later. Remember, time is malleable. It won't be too late. Another thing to remember is that this pandemic was and is part of the

very personal life journey of your loved one; it is part of their story. Eventually there may be meaning in this fact.

If there are regrets about anything (there usually are), it is NOT too late to say you are sorry or to make it better after people have died. After death communication is very widely experienced and well documented. Relationship work and resolution goes on well after death. Assume it is so. Invite your loved one to sit across from you for a conversation or in their favorite chair, write them a letter from your heart, send them your long texts. Say what wasn't said. Be open to their communication with you too! It isn't too late. Research has shown that people who still talk with their loved ones after death have less painful and more adaptive grief processes than those who do not. It is certainly hard to lose someone, but consider, just consider, that you may not be as separate as you think.

What death professionals can do

Morticians, death doulas, hospice workers and home funeral guides are well acquainted with the great passage and with grief. However up to now what our culture has deemed necessary after death were rituals designed for a different reality. Americans in the last 80 years have mainly turned the body of the deceased over to professionals within an hour or two after death, traveled long

and far to mourn at public gatherings in very scripted experiences, perhaps mediated by priests, rabbis or ministers. The focus has often turned on facilitating an event or on religious mandates (this is how we do it). After people mourn or memorialize, they usually leave each other to do the longer, harder grieving alone. The deep privacy

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of being with the body of the deceased has not been seen as very important.

Death professionals might focus less now on public experiences and religious rituals, and more on facilitating private ones: processes that support healing and personal meaning. It is time for creativity. And it is the deep privacy of grief what we must work with now. Intimate contact with the body of the deceased just after death might have a more important role. The power of this is something home funeral guides know well.

Replacing the old focus with a new one may not be as much of a loss as we first think. Morticians might learn to facilitate private or small group experiences that

are meaningful and intimate. This is a different art than presenting a body to a crowd. We can ask new questions. Such as: Hmm....could mourners sit in a circle sharing rather than in stadium style seating? What if morticians could offer at least some participation in care of the body after death (think of the deeply moving Japanese film *Departures*)? In New York, bodies of people who died without hospice may wait a long time for transport. Mortician Amy Cunningham of Brooklyn leads people by phone to have their own private "wake". "This is your wake" Amy says by phone, inviting people into the processes of direct care, "Gather flowers from your yard. Light a candle. Sing a song."

Obviously memorials may happen at some time in the future, after burials and cremations. We can help people think about this, plan them, ritualize things privately (see above). But perhaps we can also play a greater role in supporting private grief as it runs its longer course. These have always been some of the most difficult, poignant and healing times, yet people commonly feel quite abandoned in the long days of their grief after the funeral is over. Perhaps we can find better ways to support these processes.

In sum, let's open the new playbook with some of these new understandings.

Let's help each other open to finding different ways we can help. It may be a bit more interesting than broadcasting the old funerals by Zoom, though of course technology is with us, and will certainly be a partner.

Finally, let's take a moment to honor ourselves for how we are valiantly swimming the tides of this human crisis. One gift of the pandemic may be that it will challenge our rigid ideas about dying, both what we think death is, and what we think consciousness is. It empower us to be even more involved with dying, not less, more engaged and more fundamentally there than before. To this death and life educator, it seems likely that what we learn will change us forever.

For more on Jeanne's work and the School of Unusual Life Learning, please visit www.jeannedenney.com. You can also email her at jeannedenney@gmail.com.



Jeanne Denney is a transpersonal and somatic psychotherapist, educator, founding director of the School of Unusual Life Learning (SoULL) and author of *The Effects of Compassionate Presence on the Dying*. Jeanne has spent years at bedsides, contributed pioneering ideas to somatic psychology, death and grief work, and has been deeply engaged with creating the Art of Dying projects in New York City. She enjoys supporting helping professionals in their work with clients around existential fear and grief.