



# Natural Transitions

Volume 3 Issue 4

Conscious, holistic approaches to end of life



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Peace at Last

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An Exchange of Love at  
Death's Doorway

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Launching the Death Canoe

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**Veterans: Healing the Wounds of the Soul**

# GRACEFUL TENDING

by RON HOFFMAN

*At the age of ten, in the midst of his pain-filled, chaotic childhood, Ron Hoffman survived a near-fatal bullet wound. In his new memoir, Sacred Bullet: Transforming Trauma to Grace While Tending the Terminally Ill, Hoffman reflects on his journey to his current position as a national leader in the holistic care of people living with Lou Gehrig's disease, ALS. The following is an edited excerpt focusing on the practice of "tending."*

## POST-GRADUATE SHOWING UP

Tending is the active part of showing up. To show up and hold space is a form of tending for sure. It is the presence aspect, the simply being *with*, free of judgment, the need to fix, or interfere with the unfolding process. Often, however, there are some important, perhaps small steps that can be taken. The situation, if witnessed from clarity, will signal to those in attendance what needs tending, what *action* to take, if you will.

This requires presence, enough quiet in one's mind to be relatively free of internal distractions, able to take in fully the current situation. Deep listening is so, so, so very important. Deep listening ... deep, deep listening, listening with the ears of the heart, as my mentor Tom Daly says, goes so far. Sometimes I have found you can reach a level of deep listening that senses the *feelings* beneath the words, that hears the unspoken longing, the hunger for something perhaps even the speaker isn't aware of. This kind of listening could be called post-graduate showing up.

Let it be known here that I did not graduate from college, and I am at times dismissed as somebody without credentials. Who are you? they'll ask. And what's your background, and why should we listen to you, and where's the

research to back up your position? That really gets me wound up. So when I use the term *post-graduate showing up*, it's a little tongue-in-cheek, and a little maybe me asking for some respect from the PhDs.

Not long ago I stopped in on a family from a small town in central Massachusetts. I had a new lift sling to show them—a possible tool to help with mom, who was losing the ability to stand. I also had one of the nifty new portable toilet safety frames from England. The frame slides in and out, around the toilet, and doesn't require bolting to the toilet like most safety frames. Very cool. This leaves room for an automatic toilet seat lift, or bidet-washlet attachment, both of which can provide real comfort and genuine support with dignity for everyone involved.

*I'm no professor, but it seems to me there ought to be a required college course in tending.*

A lot of us just aren't comfortable wiping our husband, wife, or parent's bum, and that water fountain on the toilet can be a lifesaver. Offering tools like these is tending. It's bringing to the table something that can help, maybe just a little, to ease the stress in a very stressful situation.

I explained to the family how these items could help them. It was quite a scene. A sister, a brother, a brother-in-law, a sister-in-law, a son, and mom, Janet, in the corner, putting a brave face on the incoming reality that her days of walking were almost over.

"My aunt's funeral is tomorrow," she mentioned. "Lived to be a hundred and two."

"That's amazing," I said, picking up some sadness and longing in her words.

"I thought the senior center had a handicapped van they could bring me in. Turns out it isn't equipped for electric wheelchairs. Can you imagine that? A senior's van that can't take my wheelchair."

The son piped in, a little defensive, in a sharp New England accent, "Ma, we're looking into vans for you. I'm looking at some options. I'm looking."

"Yeah, but you won't have anything in time for Aida's funeral."

"I know. I know. I've got a call into the dealership."

"Don't go through the sales department," I said. "Talk to the manager, Eric. Ask for Eric and tell him you're one of my people. He'll take a thousand right off the top."

"That much, Ron?" Janet asked.

"You're talking her language now, Ron," the son teased. "If it has to do with saving a buck, she's all ears."

"Stop it, Tommy," his mother scolded. "It's just hard, you know, when you want to do something, something ordinary you used to do any day of your life—go to your aunt's funeral, you know?" She began to tear up.

"No worries, darlin'," I told her. "We'll get you there." I immediately got on the phone to my office to find out who was free. Both of the young men had commitments, but my assistant, Isabelle, was available. She hesitated to accept the assignment, hadn't been in the home of an ALS family. I assured her she was ready and would be providing a great service. Janet waited for me to finish the call.



“You’re all set, hon,” I said.

“Really?” Janet said. “You would do that for me?”

“Absolutely,” I assured her. “It would be our pleasure.”

I’m told by my office assistant, Isabelle—I call her “Iz”—it was one of the most fulfilling days of her life. She could not remember ever being so appreciated. And Isabelle is a woman, mind you, who was an NCAA Division I decathlete, okay? She’s had a lot of accolades in her young life. And yet the biggest impact on her was a simple act of service. Damn.

I’m no professor, but it seems to me there ought to be a required college course in tending. Just imagine how much good would be done in the world. And like Iz, the gift of tending would return double, triple what was given. It comes back and blesses you.

My point being, in tending to Janet I listened with the ears of my heart. It wasn’t hard to sense her longing, her pain, and wasn’t a big stretch to address a deep need. Her aunt’s funeral was not directly related to Janet’s ALS. A health care professional would no doubt believe me out of bounds in offering her a ride. It was going “off the reservation.” Right? But the need there was so real, and the health benefit was profound.

Let’s remember something, folks, that a human being is more than a body. Someone with ALS, or MD, or lymphoma, is more than a disease. This is a heart and a soul, and there’s a child still in there, scared and longing for acceptance, longing for love. Graceful tending takes in the whole person and brings attention and kindness to what is crying out right now.

In Janet’s case, she wanted to pay her respects to a dear auntie. If I were a by-the-book guy, it would have never crossed my mind to get her to a funeral. Not my job. I would have spent the whole time rehearsing transfers from the mechanical recliner chair to the walker or, in Janet’s case, the wheelchair. I would have pulled out my laptop, checked off the list, written my report, and moved on.

Hello! This is not an assembly line here. Agh—enough on that for now.

On another occasion the ears of my heart picked up the longing of my friend Mike Doctoroff. I had an immediate connection with him and Honey, his wife, when we first got acquainted. They had a home above a pond on the Cape. Mike savored his time down at the pond, where he could go to reflect, find some calm, relax, and contemplate his life. Sadly, the path down to the pond was steep, rocky and unstable. His illness had progressed to the point he could no longer reach the water but only look longingly at it from the house.

I could feel how important it was to Mike that he find a way home, a path to the reflective pond, his place of peace and comfort. He and Honey had considered building a path, but the steepness and length were prohibitively expensive. This would not be a walking path but one able to accommodate an electric scooter or wheelchair. It really

tugged at my heart to witness their despair at having to give up Mike’s pond. I went to work.

I pulled into the challenge several builders I knew. They came out to the property and looked, but came back with numbers and designs not anywhere in the ballpark. I talked to my good friend Doug Oakley, who has ALS and is a member of my board, and he mentioned a builder on the Cape who was a good friend of his, a man named Ralph Cataldo. Doug put me together with Ralph, who came out to take a look at the project. Ralph appreciated our work and wanted to help me find a way to get Mike back to water’s edge.

He came up with a plan involving landscaping timber, rocks, and a good bit of fill dirt. The cost would still be higher than ideal, but it was closer. We weren’t sure what to do next when Ralph came forward with an offer to build the path gratis. It was an unbelievable gesture of kindness, a big-hearted awareness of what was at stake. Ralph felt what I had. He felt the longing and responded. Mike found his way home. I can still picture him motoring down to that pond in his scooter, finding peace beside his mirroring pool.

I feel incredibly lucky to have acquired the skills to see and hear friends like Mike and Janet, and to tend them in ways that matter to *them*. Because of

the skillful tending I received from Jeffrey Duvall and Tom Daly, Stephen Foster and Meredith Little, Roshi Joan Halifax, and so many others, I have been able to mend enough that I can serve with an open heart, and on my better days, a clear, conscious mind. It is only because of the care I received when exploring and healing my inner world that I developed the practice of tending others with as much compassion and awareness as possible.

I say this in all humility and gratitude. My approach is not perfect, and not better or worse than another. It simply comes from a different place, a different set of beliefs, ones that I think offer important benefits the current health care system misses. I hear this all the time from my families. I hear them crying out for something different. In their hearts they know what tending feels like. We all know, in an ancient way, how to do this. We all deserve mindful tending. It is our birthright.

## Too, Too Much

Tending can take many forms, go in many directions. Sometimes it seems to flow naturally, to come from love and be received with love. It's so beautiful to me when it shows up like that. Other times, the situation doesn't unfold so smoothly. Perhaps it is family history, or simply the severity of the illness, but sometimes it gets messy.

Imagine being the wife of a man whose response to his disease is to come after you with persistent sexual demands. I've seen it more than once. For some reason, sex becomes the man's way of staying connected to this world, staying in his body, perhaps comforting himself that he is still a virile, sexual being. Getting an erection may be one of the few things he can still do.

The wives in these cases are really put in a bind. They're already preparing the meals, organizing the doctor visits,

managing handicapped access to the house, cleaning up, perhaps even wiping his ass. They're exhausted, overwhelmed, and distraught about the relentless progression of the illness. On top of all that, they're treated like sex slaves, required to please him whenever he snaps his fingers.

These are the guys who can be so self-centered and demanding they make tending to them incredibly difficult. I have counseled these men to practice gratitude and humility with their tenders. I suggest he may want to *invite* her to be sexual with him, *tender* an offer, and if she's too exhausted to respond, be okay with that.

One of these men I'm thinking of also became addicted to online gambling. It was another way for him to stay in the game, be a player, feel like he could have an impact on his world. The impact he had, however, was to create chaos and debt in his family. His wife found out

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about it and tried to get him to stop. “Why should I?” he argued. “What do I have to lose?”

I sometimes have to remind these men—I’ve never encountered a woman who was like this—it’s not *all* about you. Your entire family and circle of friends are *not* required to completely reorganize their lives around your care. Your suffering and loss do not give you the right to demand a pillow fluff and back rub every night at four in the morning. Your suffering does not give you the right to squander every last dime of the family’s resources. It’s not *all* about you. Everyone involved is suffering. Everyone is under stress. A little kindness and humility can be so very helpful.

Awakening to these possibilities is one of the ways healing can come out of catastrophic illness. Perhaps these men had been pampered their entire married lives. Maybe they were the breadwinners and felt they deserved to be waited on by their wives at home. Now things have changed and they too can change and grow. It does not have to become an endless stream of demands, complaints, and criticisms.

This dynamic is reversed with one of my families. The husband is tending to his wife, who has ALS. She has always been his helpmate, the keeper of the home, and has let him be in charge of all the major decisions. He will not allow anyone besides himself and his daughter to come in and tend to his wife. When it’s this tightly held, I always become nervous. Too much of a pressure cooker.

Sure enough, the daughter, who moved in with her mother and father for economic reasons before the illness, is never good enough for her dad. She is continually berated for not loving her mother enough, not caring for her in the



ways he thinks she should. She has told her father that’s not a role she wants to have. She wants others to do the nursing. She wants to love her mother in her own way. Read her books. Take her to the hair salon. Watch a movie with her.

### *We all deserve mindful tending. It is our birthright.*

The daughter wants to invite care into the home but the father won’t allow it. His wife wouldn’t mind others coming in, but she is subservient. He’s the boss and she won’t confront him. This leaves it to the daughter, who gets verbally abused if she ever mentions needing more help in the home.

I visited them the other day and the mother was lying in her hospital bed set up in what used to be the dining room. She listened to her daughter describe the situation, and she became emotional. Mom had been used to handling things, smoothing out the rough spots, and now *she* was the rough spot, the cause of the friction. She hated that she couldn’t get up and take care of things, put an end to the fighting.

I witnessed her pain and invited her to express her feelings, that it was

okay, whatever she was feeling. She wept openly for the first time since her diagnosis. I just watched her warmly, didn’t say anything more, didn’t rub her shoulder or offer her a tissue. I just let her be with her emotions until they had run their course.

Afterward she apologized, as people so often do when they cry. “No apology necessary, darlin,” I told her softly. “You’re having some feelings. It’s a good thing.”

She cried a bit more and then spoke about her situation, the hardship she blamed herself for causing, the difficulty of relying on others to take care of her. I listened to her without offering an opinion. The next day her daughter told me something had shifted. Her mother asked to see an old friend of her daughter’s, a woman she had always liked but hadn’t seen since she got sick. The daughter was amazed. “She hasn’t wanted anyone to see her, Ron. Not the way she is now. I guess shedding those tears opened her up to being seen, and maybe loved by somebody she cares for.”

I was so very grateful to hear that. When families circle the wagons and close out the world, it becomes incredibly difficult for that inner circle. Too, too much to manage for a father and a daughter alone. Time to open up and let

go. Time to grow. Time to confront the tendency to shrink back in the face of adversity. Rather, take the path of my nameless friend. Open, open, open. Stay alert to a moment of joy that wanders by. Fall into it. Be bathed by it. Let the illness serve you, be your friend and ally, rather than an adversary to be battled. There's no winning here. In yielding to loss graciously, however, so much can be learned, so much can be healed. 🌱

Ron Hoffman cofounded the Gordon T. Heald fund for ALS following Gordon Heald's death from ALS. (Ron had provided personal care for Heald until the end of his life.) In time, Hoffman's work led to the creation of the non-profit organization Compassionate Care ALS, which has worked with more than a thousand individuals, families and communities living with Lou Gehrig's Disease. For more information, visit [ccals.org](http://ccals.org).



Photos courtesy of CCALS

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- 1 Recognize the veteran (the soldier in the person, forever changed by military experience)
- 2 Understand the symptoms of PTSD (renamed Post Terror Soul Distress by Dr. Ed Tick)
- 3 Create a safe physical and emotional space (removing triggers, creating an environment in which the veteran feels able to open to the listener)
- 4 Prepare yourself and find the courage to ask the difficult questions to open the can of worms inside the veteran
- 5 Listen and validate without judgment, avoiding belittling or dismissing what the veteran shares. Create opportunities for ritual for acknowledgement of grief and loss, purification, and forgiveness
- 6 Create opportunities for atonement (action after forgiveness to make the world "whole" again)

*The Go in Peace! project plans to produce a detailed question guide to accompany the documentary, Go in Peace!, for training purposes. This will be available at a future date at [www.goinpeacefilm.org](http://www.goinpeacefilm.org). Contact Karen van Vuuren, [karenvanvu@gmail.com](mailto:karenvanvu@gmail.com).*