

Music IN THE TIME OF dying



A head injury prevents Vicki Kellogg, 51, from speaking, and now terminal ovarian cancer brings pain. But Kellogg seems to try to sing when Sharilyn Cohn plays harp as Kellogg's sister Rori Klingbeil (left) holds one hand and caregiver Donna Buturoaga the other. "I really felt it was standing-room-only. There were angels there with us," Klingbeil says of the experience.

Photos by FAITH CATHCART/THE OREGONIAN

Harp strings resonate with heartbeats. The notes of SacredFlight take death from silence to something beyond words, the gift of women determined to help people find comfort at life's end.

By INARA VERZEMNIEKS | THE OREGONIAN

NOT SO LONG AGO, IN THE DAYS OF THE frontier settlers, when people traded home for unknown country (with all the mystery and danger and loneliness that this promised), those able to be present for a death were called the privileged.

AFTER THE VIGIL:

She sits in the kitchen with a mug of tea, steam rising.

Once, while trying to describe what it was like to be with someone who is dying, she said, “Sometimes I find myself making myself bigger, so I can hold more.”

Who could blame her for being a little tired right now?

In the stillness of the kitchen, she sips her tea and thinks about what just happened: the woman, alone, in a hospital bed, a red and yellow and green afghan pulled to her chin, a trace of

lipstick, a sweep of silver hair, the steady rhythm of the oxygen machine, like the sound of an endless tide, the woman pleading in a brittle voice for someone to hold her hand.

I'm cold.

Then — the call of a harp.

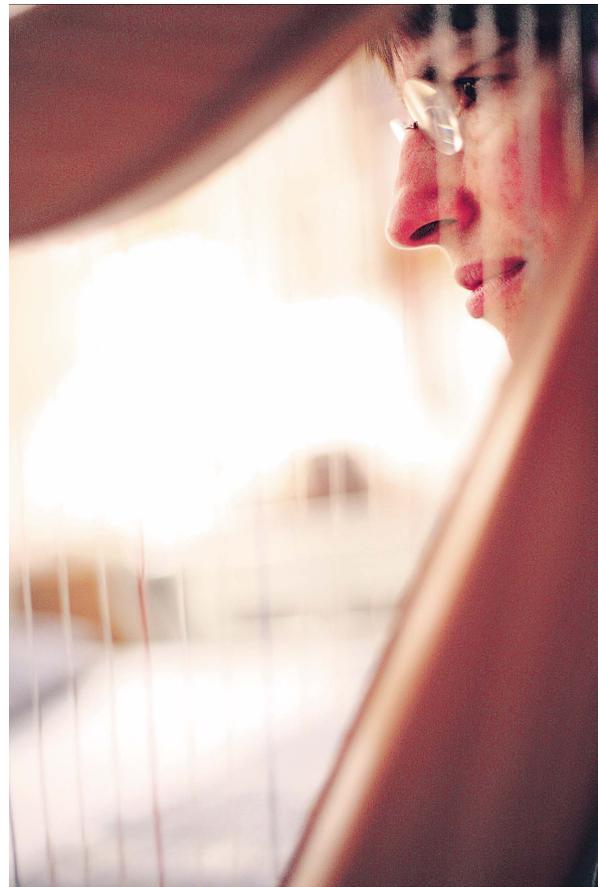
Ten years ago, when Sharilyn Cohn was going to school, training for this work with those at the end of life, playing her harp for hours, students wrote narratives after every vigil they attended, describing their experience in detail. It struck her at some point that she always wrote her narratives in the present tense, as if those experiences were a part of her now, carried forward in each moment of her life, never rooted in the past.

Now it's my turn to write.

You see, I was at the vigil that day, too. And I can't stop thinking about it.

She tells me that's because it's a part of me now, too.

What if we marked the moment (of death) somehow — what if we were encouraged to stop and reflect on what was happening?



ABOVE | At the heart of all music-thanatologists' work is a ritual known as the vigil. “It's not that we can make anything happen,” says music-thanatologist Barbara Cabot. “But music can create a space in which change can occur, shifts can happen.” Recently, Cabot held vigil for Marie Catherine Bouthillier, 91, at Legacy Hopewell House Hospice Center the afternoon before her death. Cabot tries to match the music to the moment, adjusting her playing through careful observation. “As soon as Barbara started playing,” says Angie Taylor, Bouthillier's granddaughter, “she touched my spirit. I could tell she was totally in tune with my grandma.”

THERE'S THIS THING ANTHROPOLOGISTS AND folklorists talk about called liminality (from *limin* — the Latin word for threshold) — the point in a ritual that marks a transition between two states (before and after, here and there, past and future). It's a place in and out of time. A place between.

When you find yourself in a liminal state, the normal boundaries of your life, how you think about yourself and your place in the world, are blurred, open, fluid. Nothing's fixed. It's a time of great possibility and promise; by definition, you can't emerge from a state of liminality without having been changed.

I bring this up because the story I'm about to tell you takes place almost exclusively in liminal time.

We used to put great importance on the moments leading up to death. Now, it's pretty unusual for any of us to be there to witness the end of a life. We die alone. We die hooked up to machines. We die trying not to think about or talk about what is actually happening to us. In other words, we skip over the place between.

But what if we marked the moment somehow — what if we were encouraged to stop and reflect on what was happening?

How would we mark it?

Some people believe the answer lies in music. There is, in fact, a whole field, known as music-thanatology, devoted to this idea.



At the end of the vigil, Cabot puts her harp down in order to move closer and touch Bouthillier while she sings. Voice is something that music-thanatologists do not use lightly in their vigils. “You’re adding a deeper layer of intimacy,” says Cabot. “Having that voice sometimes creates a kind of shelter where people can let go,” says fellow music-thanatologist Sharilyn Cohn.

In its modern sense, music-thanatology (Thanatos was the god of death in Greek mythology) is still a relatively young profession, developed during the past 34 years, and its principles are complicated and nuanced. It's not just about playing pretty music or playing music to entertain someone, but music used deliberately and specifically, almost like a medicine, to help soothe “the physical and existential pains” of those who are dying. Yet its inspiration dates back as far as the Middle Ages, to the monks of Cluny, France, who regularly included rituals of song in their care of the dying.

Something about this ancient approach is clearly speaking to people now. In recent years, hospitals — including several in Oregon — have created staff positions for music-thanatologists, even including them on patient rounds. Many other hospitals and hospices and nursing homes have music-thanatologists on call.

Chaplains, doctors and nurses who work in end-of-life care say it can really help (some physicians write it into patient orders), and they cite examples of patients who have needed less pain medication after listening to a music-thanatologist play, patients whose ragged breathing eased, patients who could finally fall asleep after days of insomnia.

“I must admit I started out a hard scientist and a little skeptical,” says Dr. Robert Hugo Richardson, a longtime Portland physician now working with the Center for Ethics in Health Care at Oregon Health & Science University to develop a teaching program in ethics and palliative care. “But as I saw the influence of this music on patients with either very severe physical or existential pain we were having difficulty controlling, I became a firm advocate.”

There is also talk of more intangible effects: Family members who had initially refused to accept their loved one's death, finally giving them permission to go. People who had been fearful to die, calming. A couple making the wrenching decision to remove their child from life support as the music played. A woman who had not spoken for days, whispering, as the music-thanatologist left, “Thank you.”

Can you say the music directly brought about what happened?

I don't know that I can give you a definitive answer — I don't know if anyone can. But remember what I said about liminality — the place between?

We're about to spend some time there, together. And you can see for yourself.

FIRST, OUR GUIDES: Barbara Cabot and Sharilyn Cohn, two certified music-thanatologists, who for the past six years have offered free bedside music to anyone terminally ill or dying who asks. They go to people wherever they are, in a hospice or nursing home, at home or with family, and they do this all through the nonprofit they founded called SacredFlight.

Barbara used to be an internal auditor at a bank. Sharilyn was a professional cellist and business owner. Neither had that much experience with death. Then one night, says Sharilyn, who lived in Atlanta at the time, I was home alone, flipping through the channels . . .

. . . *It was Christmas night, 1996*, says Barbara, who lived in Portland. *I was home channel surfing . . .*

. . . When I saw a woman with a harp, walking down a hospital hallway, says Sharilyn.

. . . *I saw a woman walking with a harp, teaching people how to play music for those who were dying*, says Barbara.

Something in my head said this is what you're going to be doing now, says Sharilyn.

The bells went off, says Barbara. *The gongs sounded.*

Why they knew at that moment that this was what they needed to be doing for the rest of their lives — “That part's a mystery,” says Sharilyn.

But here they are, after 2 ½ years of graduate-level training, surviving on donations and contracts from hospitals and hospices and nursing homes. (Barbara still has to work as a bookkeeper two days a week to make ends meet.) Each year they play for anywhere between 200 and nearly 300 people in the Portland area—and each of those experiences is an intimate glimpse into a moment many of us never see, or want to see, for so many reasons. Because we think it would be too sad, too hard, too depressing.

And yet, listen to how they talk about what they do:

“For the family members to allow us to be present during this incredibly vulnerable time,” says Sharilyn, “I am often left in awe.”

“It is such a privilege,” says Barbara. “An honor.”

Later, I notice that whenever they play for someone, they always say, “Thank you.”

IN THE LIMEN: A WIFE’S STORY.

My husband died July 30 of 2004. He made it to his 84th birthday and five hours past. We were together for 34 years.

He played guitar. Everyone in his family, when they would get together, would bring guitar cases. They had all these songs and memories from childhood. He played in a band when he was younger. Music was very important to him. What a birthday present to have somebody come to his room as he was dying and play music for him.

I don’t even know how to describe it. I was sitting and holding my husband’s hand. We knew his life was coming to an end. These thoughts were going through my head as the music is playing. I was watching him. It was a good time to reflect on things.

It was very — helpful doesn’t seem like the right word. It was very wonderful and important at that time to experience that.

Some women have these horrible memories . . .

I have precious memories of my husband’s last days.

— Jo Turner



The Pacific Northwest is home to a number of music-thanatologists, people committed to bringing comfort in the form of music to the terminally ill and dying. They come together annually for a public concert. Sharilyn Cohn (from left), Jane Franz and Claudia Walker take their place before a practice in the warmup circle — “an individual and collective attuning of the interior world with the exterior.”

WHEN MUSIC-THANATOLOGISTS play for someone, they refer to it as a vigil.

And it’s an interesting term, if you think about it, because it implies being watchful and awake during a time when everyone else is asleep.

Not long after I talk to Jo Turner, Sharilyn and Barbara ask if I would like to attend a vigil.

The first one I attend takes place at Legacy Hopewell House Hospice Center in Southwest Portland.

This vigil is for James Sutherland, a former painter and father of seven, who is in his final hours. Two days ago, he slipped into unconsciousness. His children, some of whom have flown in from as far away as Alaska, California and Boston, circle his bed.

Barbara sets up her harp a few feet away. The fact that music-thanatologists play harps in their vigils sometimes stops people — the harp carries such strong connotations, particularly around death and dying; angels carry harps, the sound of harps signals death. There’s also the image of it as an instrument of theatrics and flourish. “The Harpo Marx factor,” as Barbara and Sharilyn put it. I know I carried that particular preconception with me. If you hold it, too, I ask you to set it aside. Vigil music is nothing like that.

As Barbara begins to play, the sound that fills the room is very gentle and subtle and resonant, and actually a little elusive. Sometimes I think I catch the hint of something recognizable — a lullaby, a hymn — and then it shifts on me.

In fact, the music played at a vigil is always shifting, tailored specifically to each person. Before each vigil, the music-thanatologist spends some time gathering information from the doctors, nurses, social workers or chaplains, trying to figure out what’s needed most from this time. Are they having trouble breathing? Is there anxiety? Is there hurt over things said or left unsaid?

A lot of quiet observation goes on — something you might not notice unless you knew to look for it. In fact, music-thanatologists carefully watch the patient the whole time they play, looking for clues as to how the person is feeling and breathing; “listening for what is called for,” as Barbara puts it.

That’s because they don’t come in with any set idea of what to play. It is all determined on the spot as they read what’s happening with the patient, what’s happening in the room, and then they try to match the music to the moment.

For a time, Barbara sings, her voice beautiful and high and raw. I can’t really make out the words, although I feel like I know them, even though I am sure I’ve never heard this song before. Sometimes she sings only what sounds like syllables, almost like an exhalation of held breath.

One of the things that Sharilyn and Barbara once mentioned to me is that, as a principle, music-thanatologists tend to avoid playing overly familiar music. “There are a lot of memories tied to music,” Sharilyn says. And how can they know what kind of memories a particular song might trigger for someone?

As I listen to Barbara play, I realize that this edict also has another effect: When you know a song, you tend to focus on it in a different way. You follow along, waiting for a particular passage or recalling certain lyrics. But this

music asks nothing of you. Instead, it conjures a mood and allows you to drift off wherever you want — or perhaps need — to go in your mind, without distraction, giving you the freedom and space for contemplation.

Evelyn Gerardo Challis, director of pastoral services at Mary's Woods, a retirement community in Lake Oswego where Sharilyn and Barbara play, described it to me as "music that allows people to just be in the moment."

"During the time the music is played there is no other intervention," she said. "There is no one taking pulse or temperature. There is no one trying to measure anything medically. The patient is just allowed to be however they are, in whatever way they are, whether they are in pain or full of worry or doubt. There is no need to try and change them. I think this allows people to relax and surrender to what's happening, and realize that ultimately we find meaning in life by allowing ourselves to be."

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AFTER THE VIGIL:

Barbara packs up her harp and heads home.

Later that night, after two days of silence, James Sutherland will wake up. "We didn't expect it," one of his daughters, Margaret Kennedy, tells me. All his children are there. "We all got to say hello, and he recognized all of us."

The next day, he dies peacefully.

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ONE MORE VIGIL STORY.

One day, Sharilyn is called to play for a woman named Margaret Dye.

Margaret is 86 and lives at an adult foster care home in Southeast Portland. She is visited there by a hospice nurse from Adventist Health, which last year began offering music-thanatology to its hospice patients.

Margaret has no immediate family, Laura Macias, the nurse, tells me. She was married for many years, but her husband died, leaving her alone. They did not have any children. Margaret lies in a bed in a warm room, full of Christmas decorations and a photo of herself from her youth on top of the television: She is beautiful, with a cleft chin and dark pleading eyes. An oxygen machine works steadily in the corner.

It is clear that Margaret is anxious, agitated, and I hear her nurse and her social worker talking: They hope more than anything that the music will comfort her enough so she can fall asleep.

"Thank you very much for the privilege of being here today," Sharilyn tells Margaret, as she shifts her harp up against Margaret's bed frame, so Margaret might be soothed by the vibrations of the strings. "I'm going to play some beautiful music just for you. There's nothing you need to do — just relax and enjoy."

As she fingers her first notes. Margaret moans that she is cold, that her legs hurt. The nurse comforts her, pulls an afghan closer to her chin.

Sharilyn shifts into something that sounds like a lullaby, rich and dark and slow. I can see her concentrating very hard, observing Margaret intently.

Margaret closes her eyes. Shifts. She calls out briefly. I feel like I am witnessing a very intimate and intense struggle.

Sharilyn keeps playing. And gradually, Margaret's breathing deepens. Her face begins to soften. And what happens next might seem very small, but in that moment it felt like a massive comfort: Within 15 minutes, Margaret is sound asleep.

It is clear afterward that Margaret's nurse is moved to see her finally relaxed and sleeping deeply — all without having to give her more medication. And I leave there feeling moved, too, close to tears, though I can't seem to find the words for why this is, what about this moment so affected me.

It isn't until later, when I meet up with Sharilyn to talk about the vigil, that it begins to hit me.

"I see people in this work that might be alone," she says. "Like this woman today. There was no one for her, but we were there for her, and the music was there for her. And she can always go back to that now. That experience is a part of her, and she can always return to it if she needs to. It's a part of us now, too."

And now, a part of you.

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SacredFlight and music-thanatology

What: A nonprofit organization that offers free bedside music to those who are terminally ill or dying around the Portland area.

For more information: 503-241-3344,
www.sacredflight.org

For more information on music-thanatology:
www.music-thanatologyassociation.com

Institutions that provide music-thanatology vigils through SacredFlight: Oregon Health & Science University, Providence St. Vincent Hospice, Adventist Health Hospice, Kaiser Sunnyside Medical Center, Legacy Emanuel and Legacy Good Samaritan Hospitals, Legacy Hopewell House Hospice, Mary's Woods, Legacy Salmon Creek Hospital, Southwest Washington Medical Center, Ray Hickey Hospice House, Hospice Southwest

Oregon hospitals with music-thanatologists on staff: Mid-Columbia Medical Center in The Dalles, Sacred Heart Medical Center in Eugene, Providence Portland and Providence St. Vincent Medical Centers

Interested in becoming a music-thanatologist? Music-thanatologists of the Pacific Northwest are starting a training program beginning in September 2007. For more information: barbara@sacredflight.org