Lullabies For The End Of Life

Intro: Imagine you're on your death bed. You have only months or weeks left to live. The doctors have told you "There's nothing more we can do for you." That was a standard response as recently as ten years ago and many patients without families were left to die alone in hospital rooms. Those responses and attitudes are starting to change, with the growing awareness that much more can be done to bring comfort care and healing to those in the final stages of life. One of the most effective therapies is music, a form of comfort care that was used at the bedside in medieval times, but fell out of favor centuries ago. In this program "Lullabies For The End Of Life" produced by JoAnn Mar, we hear from some of the women leading grassroots efforts to return music to the dying process.

(Begins with SFX 1/Kate Munger instructing her choir)

Kate Munger has been singing at the bedsides of the terminally ill for twenty years. She remembers her first time at the bedside of Larry, her close friend who was dying of HIV-AIDS and had fallen into a coma. (To Actuality 1)

"I sat down by his bed and wondered what to do next. And instinctively I began to sing. And he had been restless and as I sang, he calmed and so did I. At the end of that experience, I felt that I had done something that was a special gift that only I could give at this moment to that person. And it was very penetrating as an experience for me."

(To SFX 2/Kate singing "It's all right/you can go/you're memories are safe with us", then fade to Actuality 2)

"It's the kind of song that I want to be absolutely sure that it's the right time for the song. The words are 'it's all right, you can go, your memories are safe with us.' And it's a song that I would come to the end of a singing session with a client who, most of the time is comatose and maybe not responding. And I would ask the family 'there's one more song I'm considering singing. And I want to make sure it's

the right song for the situation.' And it's been a powerful song for the family because it's been very difficult to say to a beloved mother or father or relative 'it's okay, I'll be all right without you. Go ahead'

(To SFX 3/medieval chanting)

A singer at the death bed of a comatose patient may seem at odds with today's modern medicine. But it's an ancient practice that goes back hundreds of years. In the 11th century, the French Benedictine monasteries in Cluny established the first infirmaries of medieval Europe. During the 200 years that followed, over a thousand Cluniac houses were founded across Europe and monastic medicine flourished. Cluny developed a series of infirmary practices that covered care of the terminally ill. Therese Schroeder-Sheker has attended many bedside vigils. She is a professional harp player and medieval scholar, to name a few of her many accomplishments. Schroeder-Sheker says the monastic infirmaries left detailed accounts of how music was used to tend the dying. (To Actuality 3)

"Since 1984, I have been studying these monastic documents. They are medical manuscripts that are the first delineation of the use of music in infirmary situations, specifically to assist a blessed or conscious death. Basically, they are all about courtesy, tenderness, intimacy, and supporting one another."

(To SFX 4/Gregorian chanting)

The music that was sung at bedside vigils was plain chant--Gregorian chanting, the music of 12th century Benedictine abbess Hildegard von Bingen are examples. Therese Schoeder-Sheker says that plain chant was ideally suited to monastic infirmary practices. This music helped relax the dying person and put him in a state of profound peace and calm. Schroeder-Sheker says this music had the effect of unbinding the ties to earthly cares and concerns--letting go of fear, anxiety, and pain. These communal services were part of the tradition of courtesy and hospitality that monasteries extended to friends and strangers alike. (To Actuality 4)

"In a Europe in which monasticism flourished, part of the Benedictine holy rule for example was to welcome strangers and pilgrims. And so if you were a pilgrim, if you were going from this place to that place, you could knock on any Benedictine monastery door at night and say 'please, may I have a room to stay and a piece of bread.' It was Benedictine hospitality that welcomed the traveler. So they had an interest just from the stand point of courtesy in caring about people. It was seen to be a really important part of civilization—to care for those who are hurting."

(To SFX 5/more chanting)

When the Renaissance period came to an end, many monastic infirmary practices fell out of favor, including care for the dying. Medieval scholar Therese Schroeder-Sheker says music and medicine parted ways, as monasteries lost their influence. (To Actuality 5)

"With the Industrial Revolution and also the Reformation, much of liturgical life was simply dropped. It was eradicated, much of liturgical life. At very many times during European history, monasteries were closed down. It's some romantic kind of legend we have to think these monastic traditions are an unbroken tradition. They've suffered just like any other group with the change of politics for each era. So these things were lost--they just became documents that scholars study."

(To SFX 6/hospital sounds--beeping, EKG, etc.)

Modern medicine has come a long way since the Middle Ages. Thanks to the latest advances in medical technology, we're living longer, healthier lives. Illnesses are treatable, many diseases are now curable. While healing the sick and curing diseases have been medicine's primary focus, death and dying no longer receive as much attention. (To Actuality 6)

"I had become interested in working with people who were dying. This must have been 1974."

Rachel Naomi Remen is medical director of the Commonweal Cancer Help Program. She describes her first frustrating experience as a young doctor trying to conduct research on the end of life. (To Actuality 7)

"And I went to the library, a major library, one of the outstanding libraries in the country and said to the librarian 'Can you tell me where are the books on death?' And she said 'Oncology and cancer research?' I said 'No, death.' And we looked at each other--it was like ships passing in the night. And she said 'Oh, thanatology.' And I said 'Yes.' She said 'Fine' and she gives me a stack number. And then I went through an experience, it was almost an allegory. I went through floors and floors of books, going downstairs. Then I went through aisles and aisles of books and journals and articles. And finally I found the section on thanatology. And it was about a quarter shelf. And as I recall, there were several copies of the Journal of Thanatology and a copy of the Bible. And that was the entire collection with respect to death."

(To SFX 7/Ralph Stanley singing "Oh Death")

The idea of death is scary. Thinking about death, talking about death is uncomfortable for many people, especially in this culture that worships youth and beauty. (To Actuality 8)

"There's a huge fear out there. I think people are very frightened of many things around death and dying."

Dr. Brad Stuart is Medical Director with VNA Hospice in California. (To Actuality 9)

"They know nothing about the process because we're not exposed to people who are dying in our culture very much. And so people have nothing but their imaginations to fall back on and unfortunately, there are some pretty nasty fantasies people have about what dying must be like and so they project that onto the process and it gets very tough for people to even think about it."

(To SFX 8/haunting music, then to Actuality 10)

"Death itself is the shadow, it's the invisible thing. Even now, we don't talk about death."

Dr. Rachel Naomi Remen. (To Actuality 11)

"I think it is part of the collective fear. I think that fear has defined the task of medicine. The task of medicine is seen as

defying death and that death is seen as a personal failure by many physicians. Many physicians are actually phobic in their reactions to death. The woman who has fifteen plastic surgeries so that she doesn't look her age, is simply part of a spectrum which ends in the doctor who keeps someone alive beyond every hope of cure because he cannot face the fact that life may end."

According to VNA hospice medical director Dr. Brad Stuart, current training of doctors draws on medical research, which emphasizes curing sickness and disease. Stuart says less than five percent of research is spent on end-of-life. The Support Study, funded by the Robert Wood Johnson Foundation in the mid 90's, found that as many as fifty percent of the terminally ill die in pain.. (To Actuality 12)

"It saddens me more than it surprises me because I think it's inexcusable."

Dr. Rachel Naomi Remen. (To Actuality 13)

"I think that pain is often something doctors don't address. We need to focus not only on dealing with disease, but also in alleviating pain. A lot of the pain that occurs is not physical. It's psychological. Responding to pain, not necessarily numbing it, but responding to it and listening to its cause is a very important part of medicine."

(To SFX 9/quiet piano music)

Psychological pain and suffering can include unrelieved fears, stress, anxiety, and feelings of isolation, abandonment, and loneliness. When Therese Schroeder-Sheker was a young nurse's aide in the 1960's, she saw terminally ill patients left alone to die. When she and other nurses expressed their concerns to the private geriatric home that employed them, they were told to mind their own business. (To Actuality 14)

"I had been very very concerned because I had witnessed other deaths at this geriatric home and the bodies of the recently dead were not treated with respect or dignity. The speed with which a body was put into a body bag to save on work, That was the main objective--to get the body in the bag and out of the room, and then an empty bed was a fiscal reality. For me, a turning point had come when I watched at

the age of 21 someone removed from the bed and in fact, they went like this--like a table cloth and the person who had just died, I heard their head clunk, clunk, clunk. And that changed me forever."

Schroeder-Sheker was so appalled by what she saw, that she decided to become a protector and guardian for those at the end of life. Not long after, her first opportunity came when she found herself alone with a man dying from emphysema. (To Actuality 15)

"We knew he was dying, he was very elderly--there was nothing that could be done for this man medically. What could be done for this man was in the realm of our humanity. So I just tiptoed over there and he was flailing because he was so frightened and thrashing. And so I did what I believe any mother or father in the world would have done if your baby is sick and crying in the middle of the night, you'd pick them up, you'd hold them. And first I just went to hold this man."

(To SFX 10/Connie Dover singing "Ubi Caritas", then to Actuality 16)

"And then when he was thrashing, I began singing my way through the Mass of the Angels. These were human responses--I sang my way through the Curiae de Sanctus and the Ado rote Devote of Thomas Aquinas, Bernard of Clairvaux's Jesu del chisme del moriae, on and on and on. I sang Gregorian chant. Then, he began to leave his own body peacefully and quietly. When I remember that day of course, it was an hour that would affect and change the entire rest of my life."

(Bring up SFX 10/Connie Dover singing "Ubi Caritas")

In 1973, Therese Schroeder-Sheker started the Chalice of Repose Project as a pilot program. It was the first program of its kind to bring music to homes, hospices, hospitals, and other institutions and to use music to tend the entire process of death. Schroeder-Sheker looked to the medieval monastic infirmary practices of Cluny as a role model for her project. (To Actuality 17)

"We receive a call from somebody--someone who loves the dying person calls me and says 'Therese, my aunt is dying in

this hospital. Please can you come?' And when you go there, it's just your job to enter as quietly as possible, don't make any big folderol that you've come. And we travel with small harps, so it's not a big production. You go in and you sit as close to the person's bed as is possible. Sometimes closer to the head rather than the feet. And sometimes you find that you're playing and they'll put their hand right on your arm and move up and down with you on the harp. This is really remarkable. Sometimes, they're too tired and weak to make any response whatsoever. It's important the dying person knows they don't have to be polite and respond. We're their servants, we've there to help.

(To SFX 11/harp music for a few seconds, then to Actuality 18)

And you play--an hour is a good visit. And you play and you play and you play. Then your job is to help dissolve time and frequently they'll enter into a very deep sleep. Frequently, they'll ask to be taken off a morphine drip or something like that. Then they'll ask their physician's permission to removed from the different kind of drug therapies. So we play and when they're sound asleep, we pack up and go quietly and tiptoe out. And, you know, it's very simple."

(Bring up SFX 12/harp music)

Therese Schroeder-Sheker's Chalice of Repose project is based on a new field she pioneered called "music thanatology." It's a sub-specialty of palliative medicine that she says is both an art and a science. Music thanatology studies the effect tone and frequency have on a dying person--how music can reduce anxiety, stress, physical and psychological pain, as well as lower heart and respiratory rates and increased levels of endorphins. Schroeder-Sheker says recent scientific research show that different parts of our bodies generate and respond to different frequencies. (To Actuality 19)

"The way you hear is completely different from the way a dying person receives. You and I are vertical and when you're really ill and you're lying down, your entire body, even when you're comatose, becomes a sensory--well, we are anyway, but most of the time, we're so hardened and we're rushing from thing to thing that we stop being receptors. When it's your time, you're very vulnerable, even when

you're comatose. And so we know now, even the surface of the skin receives tones, frequency interval. And the new science is neurophysics--we're able to measure these things now."

(To SFX 13/"The Garten Mother's Lullaby")

"The Garten Mother's Lullaby" is a song that Therese Schroeder-Sheker has played for people dying of AIDS. After playing her harp at hundreds of bedside vigils, Schroeder-Sheker says she has witnessed the power of music and its ability to alleviate physical and emotional pain and suffering. (To Actuality 20)

"Sometimes, someone has multiple cancers and enormous physical pain. They want to die, they want to leave their bodies, they want to be freed from the agony. When one person I went to--we received a call, I responded. She had multiple cancers, cancers of the everything. She had brain tumors, cancer of the spine. And her family told me she was in such unbelievable physical pain, that it was indescribable. And she had been receiving morphine for a good while. She asked, after I had played the first time, to be removed from the morphine. And the dying woman said 'trust me, trust me, I know what I'm doing. I haven't been without pain, ever, on the morphine. When you started playing, I've been relieved.' And she begged me not to leave until she went. I was the one who was frightened. She was removed from the morphine drip and I played continually for her for the next three days until she died."

(To SFX 14/more harp music)

After nearly four decades the Chalice of Repose project has greatly expanded and has provided thousands of vigils for dying patients. What started as one person's vision has now grown into an institution. In 2002, Therese Schroeder-Sheker established the School of Music Thanatology in Oregon, where she now serves as academic dean. The school offers a degreed academic program that trains music thanatologists to play harp music at the bedside. The Chalice of Repose now has offices in five states and programs for care of the dying in cities across the country.

(Bring up SFX 14 for a few seconds, then music fades out under next continuity)

Like Therese Schroeder-Sheker, Kate Munger discovered the power of music when she sang at the bedside of her comatose friend Larry in the early 90's and saw how her singing had helped calm him down. Several year later, Munger started the Threshold Choir in the San Francisco Bay Area. The choir started with a small group of women singing for the terminally ill. To Munger's great surprise, the popularity of the choir immediately caught on and its numbers quickly multiplied. (To Actuality 21)

"I had no idea that this would be as big as it is. My goal, when I started the choir in 2000, was to have 500 singers in the Bay Area by the year 2005. And now we have probably 2500 singers across the country in sixty plus choirs." So it's exceeded by far my original intention."

(To SFX 15/Threshold Choir singing)

Threshold Choir members sing for the terminally ill in homes, hospices, and hospitals.

For many of these women, singing to the dying brings healing and comfort. Kate

Munger calls their songs "lullabies for the end of life." (To Actuality 22)

"I sang for a woman who was in hospice care . There were two of us and we sang in unison. And we sang four songs, maybe four short songs which we repeated a number of times. And we sing very, very softly. And every time we sang, her eyes just--they drifted shut. The sweetest smile came on her face and she just soaked it in like a beautiful sponge. And at the end of the song, her eyes slowly opened and a big smile came all over her face. And she wasn't speaking, but you could tell that she soaked up this concentrated dose of care and kindness. And it took her to some lovely place for a very short amount of time."

(To SFX 16/more Threshold Choir singing)

The presence of the Threshold Choir at the bedside has helped open up the dying process by bringing death out of the closet and back into the community. Family members are invited to sing along with choir members. Kate Munger says members try to keep their singing as simple as possible. (To Actuality 23)

"There's generally two to three of us at a time, no more. We're singing songs that are simple and that are repetitive. And we sing very, very close to the person's ear. We like to recreate the distance between a mother's mouth and a baby's ear--so it's about eighteen inches--and we sing very, very softly. A lot of the songs we sing are rounds. But we never ever sing a round at a bedside because competing layers of text are just hard for people who are in diminished capacity to listen to three people singing three different things. So most of the time, we'll be singing in three-part harmony or in unison, or humming--a lot of times, we'll be humming."

(To SFX 17/Choir members humming)

Members of the Threshold Choir are all volunteers. They are required to attend rehearsals and learn the choir's repertoire before singing at the bedside. I was invited to attend one of the rehearsals.

(To SFX 18/rehearsal ambience)

The choir formed a large circle and in the middle of the circle was a reclining lounge chair with a blanket, resembling a sick bed.

(Bring up SFX 18 for a few seconds)

As the rehearsal got underway, choir members took turns reclining on the chair and listening to the singing. Then came my turn. I was reluctant at first, but finally agreed to participate out of politeness.

(To SFX 19/Choir singing)

Leaning back in the chair with my eyes closed, I let the sounds wash over me like gentle sonic waves. I had never in all my life experienced music as I had that day, surrounded on all sides by those glorious voices. I felt myself floating, undulating to the rhythm of those rolling vibrations. My body had become an aural receptacle. Or in the words of Therese Schroeder-Sheker, a chalice of repose. It was an "aha" moment for me. I finally understood the chalice of repose metaphor by experiencing it first hand.

(To SFX 20/Kate Munger "I brought 'Deep Peace'--that's what Shirley wants us to sing.")

Later during the rehearsal, Kate Munger and the Threshold Choir started practicing

"Deep Peace", a song requested by Shirley, a choir member dying of cancer.

(To SFX 21/Choir "Hi Shirley", then singing "Deep peace in the running way to you", then to Actuality 24)

"Ministering to the choir members who are dying. To me right now, that's the most powerful experience--to be able to develop a relationship with someone that is developed as a result of singing together and then to be able to turn that service on like a beacon onto them, who knows the song, who knows the effect she's had when she's sung to someone else and to actually offer it to her as a service to her."

(Bring up SFX 21/more "Deep Peace")

Three days after the Threshold Choir sang for her, Shirley died peacefully.

(To more SFX 21/"Deep Peace" ends)

The work of the Threshold Choir continues beyond the death of Shirley and will continue beyond the tenure of Kate Munger, who plans to retire as choir director in a few years. Munger predicts that as the baby boom generation transitions to old age, the need for the Threshold Choir will grow.

(SFX 22/Threshold Choir music starts during continuity)

The ranks of the choir are continuing to grow and spread to other states and countries. Choir members say they derive great satisfaction from sharing their songs and knowing they've made a difference in the lives of the terminally ill and their families. Some members say they feel a deep sense of calmness and connection with those who are dying. Threshold Choir member Susan Gilbert describes one of her most memorable experiences. (To Actuality 25)

"Recently, I sang for a member of our choir who was dying. She had the most beatific smile on her face when we were singing for her. And I come away from these experiences feeling more enriched and feeling less aware of my own problems, my own human problems. That we can go into it with song and with joy and come away from it, feeling that

there's an exclamation point at the end of our lives, not just a period."

(To SFX 23/more Threshold Choir singing)

"Lullabies For The End Of Life" was written and produced by JoAnn Mar. Thanks to KALW in San Francisco for use of its studio facilities. Your comments and questions are always welcome. Visit our website www.kalwfolk.org, link to our "Lullabies" page, and leave a message. Again that website is www.kalwfolk.org. To learn more about the Chalice of Repose project, visit chaliceofrepose.org. And for more information on the Threshold Choir, visit thresholdchoir.org.

"LULLABIES FOR THE END OF LIFE" MUSIC PLAYLIST

- 1. Threshold Choir, "Raise Your Voice In Jubilation" (live)
- 2. Anonymous 4, "Psalm 92: Dominus Regnavit", 11,000 Virgins, Harmonia Mundi
- 3. Anonymous 4, "Benedicamus Domino", 11,000 Virgins, Harmonia Mundi
- 4. Ralph Stanley, "Oh Death", O Brother Where Art Thou, Mercury Records
- 5. Peter Gabriel, "Jigalong", Long Walk Home, RealWorld
- 6. Gunnar Madsen, "Kerenyi", Two Hands, G-Spot Records
- 7. Connie Dover, "Ubi Caritas", The Wishing Well, Taylor Park Music
- 8. Therese Schroeder-Sheker, "Rosa Mystica", Rosa Mystica, Celestial Harmonies
- 9. Therese Schroeder-Sheker, "The Gartan Mother's Song", <u>Rose Mystica</u>, Celestial Harmonies
- 10. Threshold Choir, "Light Shine Through" (live)
- 11. Threshold Choir, "Now To Thy Loving Heart I Come" (live)
- 12. Threshold Choir, "Deep Peace" (live)
- 13. Threshold Choir, "Canonic Grace", Tenderly Rain, (self-produced)
- 14. Threshold Choir, "Resting In Harmony", Tenderly Rain, (self-produced)