



California Hospice Foundation



# CHOICES

*Empowering People*

Spring 2012

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## Turning a Life Story into a Legacy

Have you ever had a “driveway moment” while listening to a StoryCorps segment on NPR’s *Morning Edition*? You’re so riveted that you have to stay in your car until it’s finished. It’s a common occurrence when a life story is being told by one family member or friend to another during a StoryCorps interview.



*Husband and wife James R. and Karyl Meacham, StoryCorps Legacy participants at Hinds Hospice.*

StoryCorps, a national nonprofit oral history project, has been recording the stories of a diverse range of participants across the country since 2003. These stories are preserved at the American Folklife Center at the Library of Congress, with participant permission.

Last year the organization launched a new initiative, StoryCorps Legacy. StoryCorps Legacy partners with hospice and palliative care organizations to provide people with life-threatening conditions the opportunity to record, preserve, and share their stories – a legacy for loved ones and future generations.

StoryCorps unveiled this new initiative at the National Hospice and Palliative Care

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*If you or anyone you know has a need for Hospice Information and Referral services please call the California Hospice Foundation’s toll free number: 888-252-1010*

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# Turning a Life Story into a Legacy

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Organization's Clinical Team Conference in October 2011. Jill Hufft, the Community Development Coordinator at Hinds Hospice in Fresno, was in attendance. "I've been a fan of StoryCorps since it began, and since I'm an anthropology major -- preserving oral history is what anthropologists do," says Hufft. "I knew I had to go to the StoryCorps session and learn more about the Legacy program."

## Capturing memories and moments

It wasn't long before Hinds Hospice contacted StoryCorps to get involved. Nonprofit hospices pay little to nothing to participate, thanks to funding provided to StoryCorps Legacy by the Pumpkin Trust.

"We couldn't have done it without that grant," Hufft says, "or the support of our founder, Nancy Hinds, who understands the role StoryCorps Legacy plays in comfort care -- leaving a legacy behind for your family."

Participating hospices sign a three or six-month contract to record at least ten interviews each month. Two StoryCorps representatives spend four days with hospice staff and volunteers, teaching them how to conduct interviews and use the portable recording equipment.

"Since our care teams are very protective of their patients and families, we invited the entire staff to attend the initial presentation so they could understand the program and know it wouldn't compromise the care of patients in their trust," says Hufft.

The entire interview process takes about an hour. The hospice representative handles the equipment while the family member interviews the patient for 40 minutes. Jennifer Mauceri, the Volunteer Program Manager at the Nathan Adelson Hospice in Las Vegas, likes to bring along a colleague to capture keywords in the conversation so the recording is easily indexed and searchable at the American Folklife Center at the Library of Congress.

Jennifer Mauceri's first interview was with her grandmother in hospice. "It was good practice. She told the story of how she met my grandfather, giving details no one had heard before. I received the recording a few weeks ago and have listened to it several times already. It's a gift I could never repay."

StoryCorps gives a CD copy of the recording to participants, and with permission, archives a copy at the American Folklife Center at the Library of Congress. "Families also receive a numbered certificate. Generations from now, a family member can go to the Library of Congress with the certificate number and listen to their relative's story," Mauceri adds.

Segments of select interviews may also air nationally on NPR's *Morning Edition*.

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*Jennifer Mauceri with her grandmother Ruth Kane, StoryCorps Legacy participants with Nevada Senior Services and Nathan Adelson Hospice.*



*Sisters-in-law, Mildred Bober and Mary T. Zordani, StoryCorps Legacy participants with Nevada Senior Services and Nathan Adelson Hospice.*



*Barbara A. Kaiser with her grandsons, Alex and Joshua, StoryCorps Legacy participants at Hinds Hospice*

## Healing and motivating stories

A loved one's stories are kept alive for generations to come, but the impact of StoryCorps Legacy is felt by all who participate.

"It's given me an amazing grasp on how short our time is, and how important it is to be present with your loved ones," says Mauceri "I'm making a mental note of little details I wouldn't have before. I want to capture that for my kids."

Mauceri arrived for a StoryCorps appointment and found the hospice chaplain there, praying with the patient. "That set the tone for a spiritual interview. He talked about his beliefs, raising his kids, and how he looked forward to their visit the following week. He missed praying with them. He and his wife began to pray together while we were recording. Two days later, before his children's arrival, he died. They now have that beautiful loving recording."

Jill Hufft remembers a patient's interview with her granddaughter. When the granddaughter was little, the patient would sing "Say Say, Oh Playmate" to her. During the recording, they recalled those times and sang it together. "I feel privileged to be a fly on the wall during moments like that."

"Along with the recording equipment and interview tips, StoryCorps sends a list of "Great Questions," Hufft says. "I love

the answers to questions about what nourishes their soul and spirit. The stories are never about the stuff we spend our lives collecting. They're about relationships, families, friends, and experiences, never the car, boat, or house."

The interview provides comfort for the patient and family. Hufft says younger family members often ask if the patient is scared or uneasy about their final days. "Almost always, the patient says, 'No, I'm ready, it's my time. I've come to peace.' That's often a shock for the family member because they're scared. It's the first time they've discussed it. It's a sacred gift to be part of this honest and courageous exchange."

"This project has been life-changing for me," says Hufft "One of our patients told a story that gave me the courage to make a difficult life decision myself."

"Had I not gone to that conference, this would have not come to my hospice," says Hufft. "Patients, families, and staff gain so much from this experience. StoryCorps Legacy is comfort care, and that is what hospice is all about."

*Written by Deirdre Reid. Deirdre is a writer, blogger and association consultant at **Reid All About It** in North Carolina.*

**For more information on StoryCorps Legacy, visit <http://storycorps.org/initiatives/legacy>. To learn more about the hospices profiled in this story, please visit <http://www.hindhospice.org/> and <http://www.nah.org/>.**



StoryCorps Legacy participants, from left to right: Husband and wife, Neil and Ella Wiedrick, with Nevada Senior Services and Nathan Adelson Hospice; Edna Overton and her mother, Yvette Castaldo, also with Nevada Senior Services and Nathan Adelson Hospice; and 100 year old twins, Carma Drury and Cuma Schofield, with Hinds Hospice. (All photos in this issue are courtesy of StoryCorps in collaboration with Hinds Hospice, Nevada Senior Services and Nathan Adelson Hospice.)



## Hospice Homes Discussed on *The California Report*

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Most Californians would prefer to die in their homes. Despite this desire, most end up dying in a nursing home or hospital. Nursing homes and hospital stays are not only costly, they're often uncomfortable for patients and their families. When living at home is no longer practical, a more affordable option is a hospice home. For a fraction of the cost of a nursing home or a hospital, hospice homes provide end-of-life comfort care for the terminally ill.

Recently, Suzi Johnson, Vice President of CHF and President of CHF's sister organization, California Hospice and Palliative Care Association (CHAPCA), joined in a discussion of hospice homes on *The California Report*, a radio program produced by NPR station KQED.

To listen to the discussion and to learn more about hospice homes, visit the California Report's website at <http://www.californiareport.org/archive/R201204271630/e>.



*Suzi Johnson, MPH, RN, Vice President of CHF, President of CHAPCA and Vice President at Sharp HospiceCare*