

**Storytelling in the Care of the
Dying and the Bereaved**

By

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Summary

In the UK we have all but lost our traditional stories of dying – but they still exist, and we can learn to use them from other cultures.

I work as a therapeutic storyteller in a children's hospital, and as a Cruse Bereavement counsellor. I was awarded a Winston Churchill Memorial Trust fellowship in February 2006 to visit storytellers in the US and Canada who work with the dying and the bereaved.

I met with storytellers who work with children with terminal illnesses, creating stories and films. I met storytellers who work at bereavement camps, where people share their grief and hear traditional stories that help them find a common understanding. Native Americans explained that by telling stories handed down over time, they allow people to find new meanings, and see that previous generations wrestled with the same questions about death and dying.

Traditional stories are a powerful medium to express and share ideas, and the inspirational people I met in North America confirmed this.

Acknowledgements

During my time in the US I met many people (details in appendix 2) and I give thanks to them for all the assistance I received in particular Allison Cox, Gail Rosen, Joseph Galata, Darryl Babe Wilson, Dan Keding and Tandy Lacey. My long-suffering husband, Jeff Ridge, gave me loving support while I planned the trip, and at the end of the telephone and e-mail during the trip!

As I complete this report in November 2007, two people I met have recently died and I dedicate this report to them.

Corey Lee Coil aged 14

<http://www.theunion.com/article/20070825/OBITUARIES/108250138>

Cristina Perez age 24

http://www.nctimes.com/articles/2007/10/11/news/inland/3_01_5310_10_07.txt

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Introduction

I am a storyteller and a social worker by training. I have worked as a therapeutic storyteller in hospitals and hospices in the UK and as a bereavement counsellor. I have used traditional stories, personal stories, and original stories to explore the universality of experiences, or sometimes just focus on people telling their story as a story.¹

In September 2005 I applied for a Fellowship with the Winston Churchill Memorial Trust to visit the US and Canada to look at “Storytelling in the care of the Dying and Bereaved.” I was particularly interested at looking at the use of traditional stories in bereavement work, and for exploring using other forms of oral storytelling. I was successful in being awarded a fellowship, and spent 8 weeks in the autumn of 2006 travelling in the US and Canada meeting different storytellers, learning about their work and sharing experiences.

This report is on my findings looking at how storytelling in the care of the dying and the bereaved is used in performance, as a therapeutic approach, as part of a bereavement camp, as part of a festival, as a digital record of a personal story and as part of Native American tradition. It is a reflection of personal interviews, correspondence, shared experience and lengthy ongoing discussions!

Aims of the Fellowship

My aims for the Fellowship for “Storytelling in the Care of the Dying and Bereaved” were

- To explore how the art of storytelling is used in the care of the dying and with the bereaved.
- To develop and produce storytelling projects for the care of the dying, in hospitals, hospices and outreach work with local communities.
- To take this learning and disseminate it to other groups caring for the dying through papers, workshops, and shared productions.

I wanted to explore how storytelling can be used in care of the dying and support for the bereaved. In the US and Canada there were a number of arts based projects which focus on using different art forms, including oral storytelling, to work with in the care of the dying and bereaved in hospitals and hospice settings

- Telling their own stories to become part of a wider narrative for the community.
- Creating stories to share their feelings.
- Using traditional stories from different cultures that express different attitudes and responses to dying.
- Meaningful entertainment, that supports the dying and their families.

At the time of application I had been in touch with three organisations in the US, all of whom worked with storytelling with people who were dying, and who had invited me to visit them if my application was successful. However six months later, when I had been granted the award, one project had closed due to the withdrawal of government grant funding, one project had changed its focus and no longer was using storytelling, and at the third project the key person involved had left. Whilst on the one hand this showed the precarious nature of support for healing art projects in the US, it also meant that I had to rapidly redesign my project. Fortunately I am part of an online community of storytellers (the storyteller discussion list) and friends with Allison Cox, who is involved in the Healing Story Alliance (www.HealingStory.org) in the US. With her support and guidance, and feedback from the online community, I was able to refocus my project to identify and meet with individual storytellers some of whom had experience of working with the dying, but mainly with the bereaved.

Storytelling in the care of the dying and the bereaved as performance

Joseph Galata

Joseph Galata was previously the Arts-in-Education Director at the Circle of Life Hospice Foundation. I was able to shadow him for a week attending meetings, performances and making a storytelling video project.

He has designed Performing and Creative Art therapy programs using dance, storytelling, music, and drama with adolescents ages 16-25. He has trained counselors, nurses, doctors, administrators, therapists, etc. in the use of the performing and creative arts as therapy and healing processes. He also has produced and hosted the weekly radio show broadcast throughout Nevada and California "Hospice Companions."

He has traveled internationally with his one man shows "I Will Hire You As A Minstrel" and "My Grandmother's Dance" which address grief and bereavement and different responses through storytelling and dance. They are part autobiographical, part inspiration and sometimes it is difficult for the audience to know which. He feels this is an important part of the experience- that there is no one way to grieve, that the dead should be honoured, and the grieving should be allowed to find their own stories.

By taking grief into the theatre through storytelling and dance he aims to create a magical realism where there are many options for the audience to explore their own grief experience. The important part is to maintain a balance between magical and realism. He did a performance of "My Grandmother's dance" (for me personally!), and then talked me through how he runs workshops for storytelling and grief related to that. His performance incorporates real life incidents, and incidents drawn from other stories, and other people's experiences. He feels that the audience should lose their sense of what is real and what is made up (i.e. magical) in order to immerse themselves into the story. This is important; otherwise the performance becomes a therapy session for the storyteller.

However he has found that some people want to believe that his performance is real life experience, and they can feel disappointed when they realise that not all the story is Joseph's experience. That is the time for them to come to terms with the universality of experience that we all share. On one occasion he was approached by one man, a rough cowboy, who asked to speak with him, but "not in front of the rest of the audience". Alone, the man told him that his friend had died when he was a youngster and he had never grieved for him, then sobbed in Joseph's arms as he remembered. Joseph was able to reassure him that his feelings of grief were good and natural.

Acknowledging grief is an important part of Joseph's work. In one production, Joseph was working with a class on bereavement. He took Kubler Ross's five stages of grief, told a story for each part, and then composed a dance. The workshop progressed with all the young people using musical instruments and percussion to express themselves, and creating dances to dance their grief away.

Jo Tyler

Jo is an assistant professor teaching in a Masters Degree program in training and development, and a storyteller. She has performed a one woman storytelling show about the death of a former partner from cancer. She felt that she had something to share with other people through the

process of shared love, the process of living with the cancer, and eventually the way she dealt with the grief. It had a good reception and many people told her how much it had helped them to hear the story, and to come to a resolution. It gave them some hope. However one woman said "If I had known it was about cancer, I would never have come." Jo recognised the ambivalence that came from attending an event that was advertised about love and loss, and clearly about death, and yet object to the word "cancer". Death is a taboo, and sometimes there are stronger taboos- but we do not necessarily know where they may be. All we can do is offer what we have in good faith.

This ambiguity seemed to reflect Joseph Galata's experience of audience expectation, that despite publicity the audience reads into the story what they want to hear at that time, and react when something hits a nerve.

Slash Coleman.

While in San Francisco, I had the opportunity to see Slash Coleman's one man show – "The Neon Man and Me" which was on as part of the San Francisco International Fringe Theater Festival. The show was the winner of the 2005 Groucho Best One Man Show.

Described as a "delightful blend of stand-up and physical comedy" it consists of seven monologues and a musical score that Coleman plays on his guitar. The story is about a globe-trotting Jew who returns home to come to terms with the death of his best friend (a Pentecostal musician). And it is storytelling in its rawest forms showing how grief ranges from the sublime to the ridiculous, from the pain to the laughter.

It is based on Coleman's relationship with his best friend, Mark Jamison (an artist in the medium of neon from Roanoke, Virginia), who had died the previous year while hanging a sign, when his cherry picker was blown into a power line. A month after his death, Jamison's girlfriend discovered she was pregnant. Part of the money raised by the shows goes towards an education fund for Jamison's son.

I spoke with Slash who said he was delighted with the reception his performance had received, given the subject matter. Many people had contacted him and said how moved they were and how it had made them aware of their own grief. Since then Slash offers workshop in schools to help students write about a tragic event, memorise, and then perform it. Working together, watching each other recall the incidents and reinterpret it. Slash feels that this doesn't necessarily make the pain go away, but having shared their experience with others the students feel closer and more connected to others.

I attended the show with other storytellers from the area who felt that this was a powerful display of storytelling, and because it was in the theatre it was more acceptable to the public as entertainment because of the use of theatrical devices (i.e. a big neon sign dominated the otherwise empty stage.)

Storytelling in the care of the dying and the bereaved as a therapeutic approach

Allison Cox

Allison Cox has worked as a mental health therapist, social worker, health educator, health promotion specialist and prevention specialist - and for the past 20 years, has integrated storytelling into her work. She believes that stories convey important information to others in ways that few other forms of communication can accomplish. She is the vice chair and a founding board member of the Healing Story Alliance Special Interest Group of the National Storytelling Network. She is the co-editor and contributing author in the books: *The Healing Heart: Storytelling for Caring and Healthy Families* and *The Healing Heart: Storytelling for Strong and Healthy Communities*.

I had met Allison in the UK in 2004, when she interviewed me for her forthcoming book. I was please to be able to shadow her for a week, and to be introduced to other storytellers working with grief.

Each month Allison tells stories to the teens in the Juvenile Detention Center as part of her health education work for the local Health Department. Her goal is to prevent violence and substance abuse. She finds that stories offer these youth a safe venue for listening to various issues without feeling they are being lectured, and gives them ways to respond to the stories and share their thoughts. She will always ask "What are the issues or interests for this group?" and generally gets a response of broad topics such as violence, substance abuse, teen pregnancy, homelessness, etc. However, she focuses on what she sees as the bigger question - "What do you hope the audience will know/feel/think as a result of hearing stories on this subject?"

We went into the Detention Center with an open mind of what stories to tell- we both had a fallback list of stories. We had two groups of teenagers- the girls and the boys- some of whom were waiting to be being called into court for their hearings. As we entered the room, Allison commented that she didn't know any of them from her previous visit, and they were seated, sullen, clearly giving a message of not wanting to hear stories as part of the days' English lesson!

However, within seconds of Allison telling they were enraptured, giving her their full attention. She then introduced me as the English storyteller and I told a story. The boys asked me about the oldest story I knew- and I told them the outline of Gilgamesh- a Babylonian story 5000 years old which centres on the friendship between two men, and what happens after one of them dies. Several of the boys then spontaneously spoke of deaths that had affected them- a friend, a mother, a grandfather. We continued to tell stories that dealt with the theme of death, and Allison facilitated the boys to reflect on how that related to their experiences, responding to such questions as "What images in the story stood out for you?" and "What memories or feelings did you experience as you listened to the story?"

As we finished, the boys thanked us for coming, and telling them stories. One boy commented that it was the first time he had thought of his mother without crying. Another boy asked where he could find more stories like the ones we told. The teacher indicated that one of the boys was talking about his family- something that he had never done before.

In an article ²Allison has explained her process-

After the story is over, I usually ask simple question When the story brings up issues for my audience and I am in a setting such as a classroom or a group therapy meeting, I feel that it is my responsibility to bring the listeners back home safely, by offering a space between the tales to reflect, react or share with others. People will often switch from 3rd person to 1st person in mid-sentence when responding to a story. I do not push people

into this transition (and a moment of silence can be equally important), but I do invite sharing when and if my listeners feel safe. Often, I work with someone who knows the group and I may let them ask more questions regarding "Tell me how this story relates to your own experience."

I found that Allison's way of working paralleled my own, and it was useful being able to exchange views. She felt that timing was very important- and that in telling the stories you also had to take account of what was happening in the real world both in seasonal events like festivals and holidays, but also personal dynamics. When she was finishing a group she had worked with for some time, she had tried to introduce a new subject, but the members let her know in no uncertain terms that they wanted to hear about departures and holding onto good memories. Similarly in work with the dying and bereaved, death needs to be addressed sensitively and paced. She wrote³:

Sometimes, what these families need the most is just a few good hours, a good day... some time that they can remember, to laugh, to sing, to simply smile. Those are big gifts and if you can offer them that initially, then you can go back later and tell them the stories about a parent who felt angry or perhaps a child who overcame her fear of the dark. Trust the metaphorical language of stories to powerfully speak to the unconscious mind and bypass the conscious, skeptical filters of your audience.

I travelled with Allison to Vancouver, Canada where, with Mary Dessein, she was giving a performance, and running a workshop on using storytelling in working with substance mis-use. She asked me to run part of the session on issues of bereavement in substance misuse, and how I used storytelling to address that.

Andre B. Heuer

I met Andre at the National Storytelling Festival in Jonesborough, Tennessee. He had been the staff support group facilitator and grief counselor for a Hospice. He has taught and used storytelling within health care, corrections, hospice, justice circles, ministry, and social services. He is a board member of the Healing Story Alliance of the National Storytelling Network.

He works with groups, in the US and Africa, to use personal stories to provide support and to help people who have experience grief and trauma to integrate their experience in a meaningful way. He focuses on ways to use the personal stories of the patients to enhance cognitive, verbal, interpersonal, and motor skills depending on their abilities. When training professionals, the participants learn ways to incorporate storytelling with other treatment modalities such as art therapy, physical therapy, and psychotherapy and emphasise the role of personal stories in the health care environment.

He recognises that repeating of the painful elements of the experience often has a negative effect that tends to reinforce the damaging aspects of the experience and can psychologically sabotage the healing and recovery process. He feels that a bereavement counselor would need to establish the conditions for the bereaved to remember and share their experiences but also to remember the experiences that are meaningful and pleasurable in the person's life. These meaningful and pleasurable memories, experiences, and stories help to motivate the person and to promote healing.

Helping some one to remember and share an experience is only the first step in the therapeutic use of storytelling, as it is the structuring and giving shape to the story that helps the individual to integrate the experience and to gain a new perspective. The shaping and telling of the story enables the individual to take ownership of their experience while helping to create a healthy detachment.⁴ As they continue to tell the story, either their own or a traditional story, they become more at ease with the feeling they evoke, and are more ready to explore them.

Storytelling in the care of the dying and the bereaved as part of a bereavement camp

Gail Rosen

Gail is a storyteller who focuses on bereavement and end of life work. Gail found herself drawn to stories about life, death, meaning, purpose- which proved perplexing when she thought of herself as an entertainer. She tells how her mother-in-law, said, "Tell the funny ones; nobody wants to hear those sad stories." Then one day she got a phone call from a volunteer coordinator for a hospice that was running a volunteer appreciation event; and she realised that there was a whole body of stories that they would want to hear. And who could also make use of them. She trained as a hospice volunteer and developed her work from that.

When working in the hospice she rarely uses traditional stories because people come so late and at that point it is more important to hear them tell their stories, and then tell the stories back to them. In that setting she tends to work more with relatives in the bereavement work.

Gail has used stories from all over the world about people dealing with loss, about the human response to dying, death and grief – things that she believes the western culture has been uncomfortable talking about. She uses like the Buddhist story of the **Mustard Seed**. Gail says -

That kind of story honors what we might call denial, which gets a real bad rap in our culture, but such stories hold it to light because this is a normal human response. This is what grief looks like.

If we can see it in a story from another time, from another culture, we can recognize ourselves. Then we know that when – in our own pain of loss – we have recurring thoughts of how we might have prevented the death, or what we could do to bring the person back (though we know it is not possible), then we can be gentle with ourselves and know that this kind of thinking can be part of normal grieving.

She uses the story of a **person who tries to cut open a cocoon** too soon, releasing the moth, but it can't fly, because it is the struggle through the hole in the cocoon that enables the moth to fly. She emphasis with the story as a mother, recognizing the desire to try to prevent pain, but having to step back to let the person find their own way. Sometimes the way forward is just to make space and be present- sometimes the most difficult thing to do. She says that the most important thing to do is

to allow people to have their own struggle, to stand as witness, to stand and support, and not to try and fix anything. Mostly there's nothing that needs fixing with people who are grieving; you can't fix it, but you can support it; grieving and healing is a natural process, like coming out of a cocoon.

She also uses The West African story, '**Cow Tail Switch**,' is about a man who dies; his youngest son asks for him repeatedly until the older sons go on a quest, and magically bring him back.

Gail says-

For me, it is about the importance and power of remembering the dead. I think it's important to honor that kind of magical thinking: "If only I could dance the dance to make the blood flow in the veins and the heart beat again." But I can't, and yet the message, finally, in that story is, "No one is truly dead as long as someone remembers."

She has worked with different bereavement camps for adults and children in different states. I was privileged to join her on two bereavement camps- Camp Wabanaki for Adult Bereavement in Annapolis and Camp Good grief for children in Florida.

Adult Bereavement Camp- Camp Wabanaki

Camp Wabanaki is run by Hospice of the Chesapeake which is a not for profit, community-based agency in Annapolis. Wabanaki a Native American term meaning "Living at the Sunrise." The weekend bereavement camp was targeted at adults who had experienced loss through the death of a loved one, including death from a traumatic event. They offered a variety of recreational activities, creative arts, facilitated storytelling, restorative rituals and commemorative celebrations.

Participants were told they could expect to:

- Share feelings and memories in a safe, accepting environment;
- Discover that they are not alone in this experience;
- Explore the impact of the traumatic event and how it has affected their life;
- Identify effective coping strategies in dealing with grief; and
- Experience the healing power of being with nature.

A team of a professionals and trained volunteers staffed the weekend retreat. These included Gail Rosen, as storyteller and I shadowed her during the weekend. The accommodation was in comfortable, air-conditioned cabins at the Arlington Echo Outdoor Education Center. I attended a pre meeting on the Tuesday before the camp. This was an opportunity for participants to meet some of the staff prior to the weekend. Five people took the opportunity- and both Gail and I told a story as an illustration of what we did.

The weekend started on the Friday night. All the participants arrived, and there was an opening ceremony with Gail using her drum to draw people in. A story was told, and the grief counselors used a metaphor and story of sharp glass, and rolled sea glass- where the jagged edges of pan have been worn away, so that it is not so painful to handle, but still look at what the sea has brought. They then lit five candles⁵ saying

As we light these five candles in honor of your loved ones, we light one for our grief, one for our courage, one for our memories, one for our love, and one for our hope.

Everyone (including staff) then had an opportunity to light candles for the people who had died, and for naming of them. Both participants and staff and volunteers took part in this and struck the singing bowl to announce the name of the loved one.



The lighted candles for those that have died.

Then people went into small groups with a counselor to share their feeling and expectations for the weekend, finally gathering around a campfire for S'mores⁶.

Gail's session was the next day. She began her session telling several stories and then told a longer one about birds- a Native American story she had developed, which include the dead sending a message back to those in this world. She then invited the participants to relate parts of the story to their own, and how it resonated for them. The final part of the session was to write a letter to oneself, from the person that had died. They were placed in a sealed envelope, addressed to each participant, and then Gail promised to post them in a month's time. I took part in this, and when I received the letter- I realised I had forgotten about it and the process that I had undertaken before writing the letter. When I came to read the letter I was surprised and touched at how powerful the messages were- and they were not things that I would have said without the work from the storytelling.

Through out the weekend, there was a strong emphasis on the use of metaphor as a way of expressing feeling. One activity started as a trust exercise- with rolling around a circle of people, trusting that they will not let you fall, to falling off a raised platform to the waiting arms of people below – again trusting they will be there for support.

The groups moved out to an assault course and used different parts of the course to explore the tension between grief, support, and wanting to share. The most powerful exercise was a spider's web of ropes across the trees. People were told they had to go through it one by one, but once a space had been used by some people, no one else could use it. So some people had an easy climb through, but the ones who hang back, had to allow themselves to be passed through the web in the same way as they had in the earlier exercise- allowing themselves to fallback, be caught and supported as they were passed through the ropes. Showing sharing, caring and the need to let go.



Passing through the spider's web

There was also the use of collages, with images cut from magazines, representing the person and telling the stories of their life- some people had brought photos of their loved ones- others found an image in the magazines to represent them. They were glued to a card, and then sealed with varnish.

During the course of the weekend, participants and staff were invited to take part in creating a Mandala from coloured sand. When it was completed, everyone was invited to use the sand to put the initials or symbol of the loved one who had died, on the Mandala.



The Sand Mandala with initials of the loved ones who had died.

On the final afternoon all in a circle, in their own time, participants were invited to come to the Mandala, take some of the sand with their loved ones initials, and then to the sound of Gail's drumming, take the sand down some steps to a jetty by the lake, strike a bell, find a place on the jetty to let go of the sand into the lake and reflect on the life of the person who had died. Returning to the circle, there was a last holding of hands, and a short story from Gail to finish.

As I spoke with people who had been there, people reflected on the storytelling and how it had been helpful. Sometimes opening up a chance to explore something that they had been avoiding, knowing that they could talk about the story although they couldn't talk about themselves. The staff commented that the storytelling allowed them to use the metaphors in other activities so that the passing through the web was related to the story that had been told later in the day.

Children Bereavement Camp- Camp Good Grief

Camp Good Grief was organized by Hospice by the Sea, at Palm Beach, Florida for children who aged 6-13 years. They hold a Good Grief Camp in the fall, spring and summer at an outdoor camp, with log cabins at Lake Worth, Florida.



Logo for Camp Good Grief

They use the Sea Turtle as their symbol. It is one of Florida's most endangered indigenous species and their lives begin with a dangerous crossing from the safety of the nest to the vastness of the Sea. Communities have organized to protect their nests and hatchlings. They feel

that there are times in a child's life when guidance, protection and understanding are crucial. When a loved one dies many children are left with feelings of vulnerability, loss, and alienation. Camp Good Grief is there to help each child understand and deal with those feelings.

During the weekend there are opportunities for -

- Children openly discuss their loss with their peers and counselors in an emotionally safe environment
- Experience normal camp activities: face painting, arts & crafts, music, theater, games, swimming, volleyball, basketball.
- Experience a memorial service for their loved ones.

The children were brought on the Friday evening by their parents and carers, and introduced to their hut leaders. The children are separated into groups by age, enabling sibling groups to be split up to give them a chance to explore their own grief. In the evening there was a general storytelling session, and then some drama games finishing with more stories before bed time.

The next day Gail ran four storytelling sessions with different age groups, but each group was similar. She started with a simple story, and then moving into a story with more emotional themes dealing with the feelings that might arise from bereavement, without directly addressing bereavement- for example feeling grouchy, irritable etc, and another story that looked at different ways of losing things and people. Then a game of passing things to a chant – and the chant addressed the feelings of being left behind. The excitement of the game, keeping the rhythm and the chant going, allowed the children to internalize the messages through repetition and fun. Then more stories. After each story Gail asked the older children “What did you hear in that story” and “Why might I tell that at a grief camp.” The children were then free to answer in their own way and find their own meanings and associations.

There were other sessions including craft and drama which were interleaved with journaling time and group time with counselors. The craft sessions focused on making a box to keep treasures and mementos of the loved one- recalling stories to keep. The drama sessions gave small groups a tale from Aesop's fables to produce and perform it within a time constraint. In the groups they explored some of the feelings and different responses that the tales evoked in themselves, and then worked together to create a performance. At the end of the day the children were encouraged to write letters to their loved one, and at dusk they were taken outside to an open area, where a bonfire was burning. To the sound of the drum, the name of a loved one was read out, and the child or children of a family, supported by counselors walked down an avenue of flaming torches to the bonfire where they placed their letter on the bonfire, said whatever they wanted to, and then returned to the main group. Then everyone sang the chant that Gail had done with them earlier in the day and then the whole group returned to the bonfire for hot chocolate and S'mores!



The Campfire Area where the Memorial Service was held in the evening

The next day the carers came for the children. I observed several of the children pointing to Gail and recounting the stories that they had heard. One of the counselors I spoke to said “You guys give so much with the stories- we refer to them all day. The kids really get the message, it really makes a difference.”

Storytelling in the care of the dying and the bereaved as part of a festival

I visited Dan Keding, storyteller, and his wife Tandy Lacey in Champaign, Illinois. Tandy is the Director of Education at the Spurlock Museum, University of Illinois at Urbana-Champaign. In 2004 the museum had held an event “A Celebration of Souls: Day of the Dead in Southern Mexico” which proved to be one of the Museum’s most popular Campbell Gallery exhibits. Over 400 visitors placed offerings on their “altar” to commemorate those they loved and respected.

In Mexico the Day of the Dead is celebrated on November 1st for the spirits of dead children and on the 2nd November for the spirits of departed adults. The main focus is on welcoming the dead back into their homes and visiting the graves of the family, believing that the souls of the dead return and are all around them. They remember the departed by telling stories about them.

From mid October the shops are full of things to mark the days – some macabre, some sentimental. In some homes, people set up their own altars in honor of deceased relatives, decorating it with candles, flowers, photographs of the departed, candy skulls inscribed with the name of the deceased, and a selection of his or her favorite foods and drinks. On November 2nd the graves are decorated according to local custom – which may be sombre or brightly colored. They bring picnic baskets, bottles of tequila for toasting the departed or even a mariachi band to lead a sing-along, and sometimes rockets are let off as part of an open-air memorial mass.

Due to the success of the previous display, the museum planned to repeat this, and Dan and Tandy invited me to be their guest. In 2006 it was “From the Beyond: A Celebration of Spirits.” with a band Sones de Mexico performing in the museum lobby and Latina storyteller Tersí Bendiburg telling folktales of the Day of the Dead.



Storyteller Tersí Bendiburg

Band Sones de Mexico

Tersí Bendiburg is Cuban, but she has spent time in Mexico and has seen the value of the festivities. She did a mix of storytelling and sharing customs of the Day of the Dead in schools in the area, and told stories in the museum. She told me that schools have been surprised to learn about the Day of the Dead, and the way Mexicans are so much more open to celebrating and recognizing death, rather than the mainstream custom of hiding away. She recalled that telling

the tales and the customs meant that some schools were more open to supporting their pupils by re-enacting the customs in schools and addressing some of the issues that arose. The most important part, she felt, was that the children were encouraged to tell the stories of the people who had died in the context of celebration and joy, rather than sadness and grief.



La Muerta- the Madame Death with the Band Sones de Mexico

The sense of celebration and joy was vividly portrayed by the band Sones de Mexico who played very lively music, all traditional in style and specifically written for the celebrations of the Day of the Dead. They were accompanied by La Muerta- Madame Death who wore a skull face mask. Her exuberant dancing conveyed the energy of life, and the audience joined in creating their own movements and steps. One woman commented "I never knew that remembering the dead could be such fun!"

Storytelling in the care of the dying and the bereaved as a digital record of a personal story

Gail Rosen

Gail also addresses bereavement in other powerful ways- taking oral history and presenting the stories that way both as performance, and more recently as a film and digital record. She went to hear Hilda Cohen, a Holocaust survivor speak at a Yom HaShoah event, which is a Holocaust day of remembrance. Hilda told her story, and afterwards there were refreshments. Gail was talking to another woman who said, "What do you do?" and she said, "I'm a storyteller." Hilda was standing behind the other woman with her back to Gail, but Hilda turned, and came towards Gail. Gail remembers how Hilda said

"You said you're a storyteller?" Yes. "Do you tell stories about the Holocaust?" Gail said, "No I don't feel entitled to tell them. They're not my stories, but they need to be told. I'm honored to have heard your story. I hope you tell it for a long time, and I wonder who will tell it when you no longer tell it." Hilda smiled and said, "You tell it."



Gail Rosen with photographs of Hilda Stern Cohen

From that Gail began a series of interviews with Hilda, who fell ill shortly after they ended their interviews, and died in 1997 less than a year later. Since then Gail has traveled to Poland and told Hilda's story at the Auschwitz-Birkenau Museum to more than 150 of their guides. Dr. William Gilcher, at the Goethe Institute has been supportive of her work and Gail has traveled to Germany several times, and a film of Hilda's story is being made.⁷ Gail presents Hilda's story through storytelling, reading of Hilda's poetry and Hebrew chants. She feels that it is important to tell these stories as close to the source as possible, keeping faith to the story as it was told and not changing it to suit different situations. She has found that by taking on Hilda's story to tell in different communities, that people have approached her to say how touched they were by the story and that it had given them strength to deal with their own bereavements.

Joseph Galata

During the week that I was shadowing him, Joseph was working with a group of children and young adults with Epidermolysis Bullosa. Epidermolysis Bullosa (EB) is a rare genetic condition in which the skin and body linings blister at the slightest knock or rub, causing painful, open wounds. At its mildest, the condition is confined to the hands and feet making holding things and walking extremely painful. In more severe forms all the body is affected and the wounds heal very slowly, giving rise to scarring, physical deformity and significant disability. People with the more severe types of EB also have an exceptionally high risk of developing skin cancers, and in its most severe form, the condition is fatal in infancy. People with EB are often referred to as "Butterfly Children" because of the extreme fragility of their skin, like a butterfly.

Joseph had become involved with one family where three children had EB, and in order to support the family, and create further awareness of the condition Joseph decided to shoot a short video called "Can you make a Butterfly Smile" and submit it for a national competition. The shoot occurred during my stay, and I was privileged to observe and participate with the children and young people. Joseph was working with Cristina Perez a young poet aged 24, and who has EB. She maintained a website at <http://www.ebpatient.com/main.html> where she detailed her experiences with EB. I had several discussions with her, in between filming. She said that storytelling for her was important- not for the transformation because she knew there would be no magical wands for her - but it was the promise of hope for a better future. Stories didn't always turn out the way you intended, but something always happened and that sense of hope sustained her. Cristina spent her time creating a website as a resource for people with EB, sharing information and creating an on-line community. The video took the form of her telling a story to Joseph about Butterfly Children and the discrimination they experience.

The other children taking part in the video shoot were teenagers and one child of about 6. One of the teenagers, Corey, the said that telling stories about EB children was important, so that other people knew what it was like for them. During the course of filming it was announced that the House of Representatives and the Senate had voted to formalize the last week of October of every year as National Epidermolysis Bullosa Awareness Week. As part of the day, and to celebrate Corey's 13th birthday, everyone released butterflies. The video was subsequently edited and submitted to the competition. It wasn't a winner, but it has since been used in various EB sites and in school EB awareness projects.

Sadly both Cristina and Corey have died since I met them in Reno.

Working with Joseph gave me an opportunity to see how storytelling in performance can address grief and the importance of being clear about the boundaries. I had the opportunity to take part in the use of video and digital storytelling to convey the community story of the EB children and young adults , and their understanding of how traditional stories and the stories they were making were related.

Centre for Digital Storytelling

I spent three days taking a class at the Centre for Digital Storytelling (CDS) in Berkeley, California. In 1993, CDS's founders developed a workshop environment that assists people in creating video stories from their family photos and home video.

Since then they have helped over 10,000 people tell the stories of their lives, or the lives of their loved ones. The stories have covered every conceivable topic: tales of survival and achievement; corporate brand stories, travel adventures; love stories, health and healing; oral histories about cultures, historic periods, and work experiences; and memorials to loved ones. BBC Wales and BBC VideoNation have also visited them, and brought some of these techniques to the UK.

I was interested in how these may be used in the process of bereavement. It would seem that being able to make a record of someone's life and achievements through a 3 minutes video/photo compilation with voiceover could be very helpful. I attended the three day course, having taken a mixture of images with me and found myself composing a story about my deceased mother, and her brother. Jo Lambert, director of the centre, said that he felt that there was great potential for use of digital storytelling in bereavement work, and cited some of the work done by Rosetta Life in the UK, that works with people in hospices to help them tell their life story in different formats, including digital storytelling. He commented that several people had attended their workshops to create memorials for loved ones who had died, and on the course that I attended were two other women doing something similar.

Jo acknowledged that digital storytelling is different from oral storytelling or written storytelling. Its focus is on telling a short story about personal experiences, and using photos and video clips to support that. The digital stories are generally about 3 minutes long, but very powerful and effective. There is increasing use of digital storytelling in many fields, and there are clearly opportunities for the dying and bereaved to use the format to tell their own stories.

Storytelling in the care of the dying and the bereaved as part of native American tradition

Darryl Babe Wilson



Darryl Babe Wilson

Darryl Babe Wilson is a Native American from Achuma- We on his father's side, and Atsuge-We on his mother's side and a member of the California Pit River tribe. He has a PhD from the University of Arizona, and is acknowledged to have worked hard to preserve the oral traditions of native people. He won the 1999 Wordcraft Circle Writer of the year for his autobiography, which details the death of his mother when he was young, how that affected his life, and relates it to traditional Native American rituals.

I met him at his home in Carson City, Nevada. He had a stroke some years ago, and is now in a wheel chair. However he was willing to meet with me to discuss storytelling in the care of the dying and the bereaved and we had corresponded at length before I met him.

He was keen to point out that for Native Americans storytelling had different meaning. He felt that the American meaning of "storytelling" meant amusement or lies, but he viewed "storytelling" as oral literature. The difference is entertainment versus the transference of the histories of a non-writing people to the next generation. He had strong views about the role of Europeans entering the country and imposing distorted values while casting native traditions aside. He felt this had meant that generations of Native Americans were torn between their own cultures and the mainstream culture. This in turn had affected the way the Native Americans had learned and responded to their native traditions. He recognized that different Native American groups held different oral traditions, but they were a learned code of behaviour with core values.

His book "The Morning the Sun went down" details the way he was removed from the Native American culture after his mother died, and he did not return to it until later in life. In this way he missed out on many of the rituals and rites of passage of adolescence, and only came to them later when he embraced them with passion. He described how Native Americans see Life and Death, not as "beginning" at birth and "ending" at a grave, but as a continuation – although in an altered form. "Going on ahead" is used to say that someone has "changed worlds". This phrase derives from the oral literature that says that

the spirit of the individual is alive and traveling. The spirit travels to the island in the west. Once there the spirit is judged. If the human history that the spirit just left was good, the spirit passes from the island and continues the journey on the river-of-stars, *Ume juma*, *willo'e'ta'oo*, the Milky Way. While on this journey through the stars the spirit collects

wisdom. Upon ending the journey from where it began, the spirit presents to the people new wisdoms to share.

It is not explained in the narrative what form the spirit returns in. Since wisdom usually comes to the people as a dream, it is very likely the spirit takes the form of a dream because that is how everything began. The dream appears, usually in solitude, to many dreamers – the basket maker, the hunter/fisher, the medicine man/woman, *Wehelu* (leader, chief, giver of life), children, thinkers, the respectful, the responsible historian. Dreams also appear anywhere at any time. In the village the dreamer was always expected and searched for in the new generations. When located, that special person was well guided because dreaming was the most important element ensuring a continuation of the “way.”

There is a vast difference between “knowing,” and “believing.” In our “way,” to “know” something is to enter the realm of a greater positive. To “believe” is a notion waiting for a convincing argument as it prepares to change in its constant search for *wa’tu*. *Wa’tu/ah’lo* is explained by the old ones: “Everybody has a *wa’tu* and *ah’lo*. These are umbilical cords. The *ah’lo* connects one to its mother and to this earth. The *wa’tu* is a spiritual connection with the universe and all of the power everywhere.” To understand and become protected by the wisdom of “knowing,” *wa’tu* ensures that the person’s spirit will continue to the Milky Way, will glean wisdom on that journey, and will return to the people, appearing in a dream.

Darryl had a stroke which has left him disabled. This has led him to think more about his life and eventual death. He said

It kind of made me wonder, when you said you were looking for stories and death. The concept of death is so much different in my people, from native people on my side of the river, to people on the other side, to people away, and for sure very different to Christians.

I have had difficulties and overcome them, because I come from a long line of storytellers and dreamers, who have the history, and have given the history to me. and that has kept me going very good, I have had a lot of pain and aggravation, and I got a lot out of the stories I was told. I had a foundation of a life situation, that never entertained death as something to be fearful of, or shudder in front of- not even death.

Its like summer turns to winter, to spring, back to summer. In between autumn is there. When the leaves fall off the trees are dead. But they are not dead. They are just doing some thing else while they are preparing for spring. My own people would say that they are dreaming, wintertime is the time the plants are preparing for spring, dreaming about making fruit for future generations to harvest . Death is a change from that person walking around and dealing with people. Its another part of journey that was decided when the stars sprinkled the heavens- not your destiny to die, but to go on a journey. You go on a journey that destiny had decided long, long ago. Heaven is another phase of a journey, and not a destination.

The journey is not about going to heaven. There is power and spirit in the person- if good, have a good sprit, kind heart, gentle honest, true, then your spirit will leave your body (and) will do whatever bodies do, and if you are a good person you are put on this journey, and eventually come to the milky way , and begin a journey over the river of stars, which comes back to where we are sitting in the spiritual sense. We are at the beginning of the Milky Way, and at the end we are exactly on the circle. It all comes back to the same pace. But it is a long journey on the bridge of stars. And the purpose for going to the river of stars is to gather wisdom to come back to here and share that

wisdom with the next generation. At some point I will change, I will be here to give wisdom to the next generation. Not like I am now, broken down and with a stroke.

That's the difference between wise people and people of knowledge- people of knowledge gather knowledge here. People of wisdom gather knowledge in the River of Stars. My people are dreamers, Wisdom comes to anybody, in dreams, How did the old Indian make arrowhead out of rock, make fire- these all come in dreams. It depends how we react to a dream that causes parts of the dream to materialise physically. How did they make a canoe? Trial and error? I don't think that works. Some one was dreaming how to float on the river like a leaf, and then they figured it out by dreaming, the dream came, the canoe came and they could float. Through dreams wisdom comes to people. You come back as a dream- not as a human giving orders or commandments or parables. And if your dream is accepted at the right time, you give wisdom.

Darryl's view of life and death was balanced on the traditional stories that he knew, and had to retrieve as an adult. He was particularly concerned that younger Native Americans were influenced away from the old traditions by mainstream culture. Whilst disabled by the stroke, and mindful that his own death was that much nearer, he also knew that the traditional stories gave him a way of understanding the world that gave him reassurance personally, but was at risk of being left behind if the younger generations did not have the opportunity to hear, learn and respect the stories too. It seemed that Europeans brought many diseases- but the worst one was disrespect.

Conclusion

I met many more storytellers than I have been able to record here. Each of them used stories in different ways to help and support people who were dying and bereaved. Whether the stories were traditional, stories about other people, or their own stories it is clear that there are many ways to approach the use of storytelling, and the value of oral storytelling is in the process of using words and images to convey feelings.

We do not always plan what we say or feel, but being able to explore those feelings through traditional stories, applying them to our own experience helps us to appreciate and understand the universality of grief. In my experience, the newly bereaved want reassurance that the feelings they have, physically and mentally, are normal. The stories we can tell, help people to understand that grief is normal, and at the same time offer hope that there is a path through.

The experience I have gained through this Fellowship has allowed me to be open to exploring and developing the use of storytelling in its widest sense to support the care of the dying and bereaved.

In September 2007 I presented at the Cruse Bereavement Care conference on storytelling with the dying and the bereaved, using the material gained in this Fellowship and I have been asked to run workshops in a number of different places. People who have already been on my workshops have said how useful it has been to them, and to consider the possibilities in their own work. The breadth of experiences I had on this Fellowship has given me a depth and breadth of knowledge to share with others more fruitfully.

APPENDIX 1

Timetable and key people and events

Dates 2006	Where	Meeting :-
7th -13 Sept	San Francisco California	<ul style="list-style-type: none"> • Ruth Fraser • Jackie Baldwin • Patricia Jain • Jane Crouse • Slash Coleman
13-18 Sept	Berkeley, California	<ul style="list-style-type: none"> • Centre for Digital Storytelling • Jo Lambert
18th to 24th Sept	Reno, Nevada	<ul style="list-style-type: none"> • Joseph Galata • Darryl Babe Wilson • Andy Black
24 Sept to 4th October	Seattle Washington (plus weekend in Vancouver , Canada)	<ul style="list-style-type: none"> • Allison Cox • Mark Bassett • Mary Dessein • Merna Hecht • Billie L. Barnes • Members of Seattle and Area Storytellers • Marylyn Milner • Members of Vancouver Storytellers • Mary Gavin
4th – 10th October	Tennessee	<ul style="list-style-type: none"> • National Storytelling Festival • Andre Heurer • Diane Rook • Lani Peterson • Elizabeth Ellis • Loren Niemi • Dovie Thomason
10-16th October	Baltimore Maryland	<ul style="list-style-type: none"> • Gail Rosen • Jo Tyler • Cricket Parmalee • Ab Logan • Camp Wabanaki
16th-24th October	Champaign, Illinois	<ul style="list-style-type: none"> • Dan Keding • Tandy Lacey • Tersa Bendiburg • Janice Del Negro • Kim Sheahan • Day of the Dead celebration at Spurlock Museum
24th- 26th October	Chicago	<ul style="list-style-type: none"> • My contact had the wrong dates and was out of town!!
26 th - 30th October	Del Ray Beach Florida	<ul style="list-style-type: none"> • Gail Rosen • Camp Good Grief

APPENDIX 2 Endnotes

¹ My work in this field has been greatly influenced by “Storytelling in Bereavement” by Alida Gersie, which I highly recommend.

² Allison Cox 2000 – “Storytelling as a Journey Down the Healing Path” on www.healingstory.org/articles/journal_issue_1/Storytelling_Journey_Down_Healing_Path.html

³ As above

⁴ See “Using Personal Story Within Healthcare” By Andre B. Heuer and Charlotte Phillips http://www.healingstory.org/articles/newsletter_spring_4/personal_story_healthcare.html

⁵ I later found this to be based on Holiday Help: A Guide for Holidays and Special Days by Sherry Williams. The text can be found at http://www.selfhealingexpressions.com/grief_rituals_holiday_memorial.shtml

⁶ A s'more is a traditional campfire treat popular in the United States and Canada, consisting of a roasted marshmallow and a slab of chocolate sandwiched between two pieces of graham cracker!

⁷ See www.gailrosen.com/holocaust/holocaustcontent.html