Supporting People with Intellectual and Developmental Disabilities through Grief and Loss

An Opportunity to live out our Vision
Presenters

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Why this series?

• New national working group on Healthcare Decision Making formed by the Association of University Centers on Disabilities in response to experiences of people with intellectual and developmental disabilities and their families in acute care hospitals around the country.

• We are part of that working group, along with Trace Haythorn representing ACPE.

• Personal experiences as chaplains and as a parent.
  • The story of Brian, and encountering patients with IDDs in all areas of the hospital
What is “normal?”

Mom? What is...Normal?

It's just a setting on the dryer, honey.
Impacting grief and loss

- Assumptions about the ability to understand, i.e., disenfranchised grief.
- Assumptions about ability to feel.
- Assumptions about your capacity to deal with that situation personally or as pastor.
- Assumptions about the continuity of grief, e.g., “chronic sorrow” of parents.
- Assumptions about the grief “process”
- Broad (and usually negative) prognosis
- Key strategy: Reverse the questions so they are not about “them” but all of us.
Theological issues

• Why the disability? Why me? Why my child?
• Whose fault? Paradoxes of responsibility.
• Faith, healing, and cure. Being an object of the assumptions of others.
• Spiritual history and stories: too often abuse and neglect.
These often involve grief and loss

- Pre-natal and post-natal diagnosis.
- Diagnosis later in childhood after problems or issues discovered.
  - Kathleen Bolduc: *His Name is Joel. Finding God in a Son’s Disability*
- Accident or trauma leading to cognitive disability
- Aging, end of life transition

But the list gets longer for families and individuals...
Welcome to Holland

by Emily Perl Kingsley

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.
So you must go out and buy new guide books.
And you must learn a whole new language.
And you will meet a whole new group of people
you would never have met.

It's just a different place.
It's slower-paced than Italy, less flashy than Italy.
But after you've been there for a while
and you catch your breath, you look around....
and you begin to notice that Holland has windmills....
and Holland has tulips.
Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...
and they're all bragging about
what a wonderful time they had there.
And for the rest of your life, you will say
"Yes, that's where I was supposed to go.
That's what I had planned."
And the pain of that will never, ever, ever, ever go away...
because the loss of that dream is a very, very significant loss.

But... if you spend your life
mourning the fact that you didn't get to Italy,
you may never be free to
enjoy the very special, the very lovely things...
about Holland.
“Typical” experiences heightened by disability

- What do I do now as new parent?
- Celebrations of birth and other rites of passage
- Responses by others
- Search for services and supports, including congregation
- One new crisis or transition can kick up initial grief process
- Moving into adolescence
- From adolescence to young adult
- Moving out of the family home
- As adult, dealing with loss of relatives and parents
- Helping adults with IDD prepare for their own death
Grief at different ages

• Death and Grieving for children
  • Explain it as fully as possible.
  • Use a social story.
  • Keep it concrete.
  • Avoid euphemisms...use the d-word!
  • Talk about memories.
  • Provide reassurance.
  • Try to keep other aspects of life as consistent as possible.

(adapted from Pathfinders for Autism 2011)
Behavior speaks loudly

• Revisiting Brian’s experience
  • What initially looked like a suicide attempt was not
Moving into adolescence

• Heightening the issues of friendship and social connections
• Who’s in, who’s out?

• Is it changing? Perhaps. Some growing evidence of mutuality of relationships and friendships.

• Opportunity for congregational youth programs to explore meaning of identity, community, and faith tradition
Young adulthood

- Loss of friends moving away
- Search for meaningful adult roles after education entitlement ends.
  - Story, family, congregation, youth group
- Loneliness and issues of intimacy
- Staying home or moving out. Is there a choice?
  - About 80% of adults with autism live at home.
Adult losses:

- Parents and relatives
  - Far too frequent inability to participate in end of life rituals and customs
- Loss of staff in system where turnover is rampant
- Loss of friends from multiple transitions
An agency wide spiritual assessment:

- CPE student in New Jersey
- Conversations with people served about what was most important to them.
- Answers compiled, compared, and organized.
- Use of Wordle graphic: The larger the letters, the greater the number of similar responses.
I miss my friends at Woodbine. I really, really miss them.

My Mom died. My Pop-pop died. I don’t like to think about Woodbine.

I need help to get there. My best friend doesn’t live here anymore.

Why does cancer kill a person? My best friend died. I need a friend to sit with.

Is God in nature? I need someone for my kids.

Who will watch my cats? Where do people go when they die?

I can’t talk to my friend in Aneara? How can I see my friends from New Lisbon?

I don’t like to think about Woodbine. I know I’ll never be able to drive.

Where is Heaven? I can’t live alone anymore.
In Old Systems of Care

• Aging was often out of sight, out of mind, and life expectancy was much shorter.

• Death a “Key Indicator” of
  • Loneliness and loss of connection
  • Injustice, no power, at hands of family and/or system
  • Abandonment
  • Family wounds
    • Reliving the history. MDC story
In “New” Systems

• Loneliness often still there: Who are the unpaid friends?
  • http://www.declarationforindependence.org/blog/the-most-innovative-projects-start-with-relationships

• Evidence of disconnection even while living in “the community.” Does not mean you are part of it.

• Disconnect between family and staff often still there over issues of care. Antagonists rather than partners.

• Routine medical care can become end of life issue—quality of life assumptions

• Decline and aging as fundamental challenge to philosophy based on helping people learn, grow, and develop according to their potential.
New Challenges and Crises

• Death as “double injustice”: Two “Why’s?”
• Disability enough to deal with, why this?
• Aging, disability, death=curses
• Anger by staff and others at
  • Family
  • Other staff
  • Unrecognized losses by management and confusing policies
• Death as an “unusual incident,” necessitating a “critical incident report” and often a “unusual incident review.” Mistakes can be seen as criminal, e.g., Danielle’s Law in New Jersey
Challenges and Crises (cont.)

Processing of Grief and Loss:
• By families and friends
• By transitions and change, including turnover. Turnover increased by unrecognized grief
• By staff with many different experiences of grief and loss and many different cultural assumptions, beliefs, and practices
• By stigma and stereotypes
Challenges and Crises (cont)

Pressures and Paradoxes

- “They don’t understand” vs. “Move on quickly.”
- Importance of relationships, not program or plan.
- Pressure to fill the empty slot, bed, or place at the table
Opportunity

- Revision not as decline but as journey.
- How can we help that to be as self-determined as possible? What is really important to you now? Retirement and endings.
- To build new networks of care and support for people with developmental disabilities, their staff, and/or families.

This is a key entry point for chaplains and clergy for pastoral care, congregational connection, and education on core spiritual issues, including helping others deal with death, grief, and loss. Who you gonna call? Many do not know.
Key Strategies for Helping Adults, Family, and Staff

- First, recognize it and welcome it. “Grief delayed is grief denied and grief denied is grief delayed.”
- Create a safe place for it. A sanctuary.
- Be alert for behavioral expressions.
- Assist in appropriate behavioral expressions, e.g., cards, photos, letters, talking about feelings and memories.
- Search for the connections that are there. Again, see: http://well.blogs.nytimes.com/2016/04/01/my-banished-brother/?ref=health
- NJ CPE Story
“What can I say?”

“I know an individual, close to my age, with Asperger’s, whom I met in college. When discussing the death of someone we both knew he said, ‘Congratulations!’ I felt he knew he was supposed to say something that acknowledged the death but did not realize that we do not say congratulations at a funeral or in the context of the death of a loved one.” (Wong 2013)

Provide alternatives:

• “My condolences”
• “I’m so sorry”
• “I’m keeping your family in my prayers”
Key Strategies for Grieving

- Accurate and **honest** information and support to process questions/feelings
- Enable maximum involvement in the social and spiritual activities surrounding death
- Keep connected with key supportive relationships: Who would you turn to?
- Maximize opportunities for expression of grief and condolences.

- Jeffrey Kaufmann, Helping Persons with Mental Retardation Mourn.
More strategies for grieving

- Share the narrative of illness, if appropriate.
  - Differentiate the illness of the person who died from simply getting sick, or the person might assume all sickness leads to a similar death.

- Well-meaning protection vs. denial of reality
  - Loss is hard and grief can hurt. But we offer an individual the autonomy of experiencing it as a way to honor their personhood.
Core pastoral roles

- Presence...with willingness to ask about story.
- Guidance...counsel...search for meaning
- Advocate.
- Building community of support. Perhaps in congregation, but also in consultation with families and agencies.

Many agencies struggling with grief and loss issues. Opportunity for pastoral and community outreach.
Pastoral responses

- Hear the stories and the feelings
- Model radical acceptance & inclusivity
- Find other parts of identity and share them (i.e., see the strengths and interests)
- Listen to behavior
- Talk to those who know the person best
- Symbol and ritual can be crucial
- Simple but not childish
- Use core values of patient and family centered care
- Advocate for participation in all the rites of grief.
Anticipatory Grieving by Providers

• Moments to teach and talk about death and loss with those we support.
• Build relationships with local resources so the comforters are not strangers, e.g., a grief response team.
• Address and honor spirituality.
• Staff in-service about the pervasiveness of grief and loss.
• Loss assessments, planning ahead with family and guardians.
• Person centered planning for end of life wishes. See resource list for examples developed specifically for people with intellectual and developmental disabilities. (and really useable for anyone...next slide)
Mary Katherine’s
One-Page Profile
Done after the loss of her partner Tom
10/2010

What People Need to Know About Me Now
Most of the time I am OK.
When I am feeling sad or am grieving I will probably want to be alone.
When I am feeling good I may still want to be alone or I may want company.
I will let people know when I want/need company and when I need to be alone.
I don’t need any more books on how to grieve; I am writing one of my own every day.
My attention span is not very long so please don’t be offended if I cannot keep up a long conversation.
Short visits are best but try to call first.
Phone calls are good but texts and e-mails are even better.
Sometimes I am up in the middle of night and might e-mail, text or play on Face Book, this is not a matter for concern but if you are up too feel free to respond.

Things I Don’t Need
Food, I like to cook and need to do more of it
Books on grief
Taking sleeping aids, I would rather face the night even if it gets long

What Helps Me Feel Better Right Now
Being in my home
Prayer
Listening to music, especially Van Morrison
Spending time with my dogs and cats
Being with, talking to, Tom’s friends and my friends
Working out at the Y
Going out with friends but leaving when I need to
Going to hear live music, especially people that Tom and I liked to listen to together
Mystery novels
Going back to work

Other Things
If you have questions, don’t be afraid to ask them. I am sure it will not be the first time.
If I am telling you “too much” feel free to stop me
Sometimes my body hurts and I may not want to be touched
Sometimes a hug is the thing I need the most
If you need a hug from me or are having a hard time I want to help. I know that I am not the only one who has lost a loved one
Paradoxical Roles for Caregivers

- Staff, family, and/or friend.
- “Be with” as well as “do for”
- “Care for needs” as well as “celebrate gifts.”
- Specialized supports vs. “give it away”
- Know what we don’t know, and use that to invite others in to a network of care.
Ministry with Professionals to Help Recover the “Profess” in “Professional”

• Capacity to journey with others: loyalty, fealty
• Capacity to deal with the tough ethical and spiritual questions that disability and death so starkly raise for us
• Capacity to recognize and celebrate those holy moments of growth, encounter, shared learning
• Capacity to give thanks for discovery, meaning, and gift to us
• Capacity to sacrifice, give up, for sake of others
Resources

• Listing of current resources, go to:
• Resource listing for this series.
• Also go to The Quality Mall, www.qualitymall.org
• Hospices beginning to address grief and loss for individuals with intellectual and developmental disabilities. Clergy can encourage collaboration between hospices and service providers.
At the End of the Journey

- Caring for and with the whole community
  Families, friends, staff, connections

- Creative rituals of loss and celebration that involve people through all the senses.

- Funerals can be experiences of redemption and reconciliation.

- Honoring individual differences and community as a whole.
Questions and Discussion