Bereavement Support for Adults with Intellectual Disabilities

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Working with Adults with Intellectual Disabilities, Their Families & Caregivers

• Relationships With Families & Caregivers
• Myths About the Individuals
• Challenges of Providing Hospice Services

Decision Making

• Most of the patients who have ID will have Legal Guardians.
• Those legal guardians will be the only person who can sign the legal paperwork for admission to hospice.
• The guardians may give the person freedom to make some decisions; others expect to be involved in every step of the process.
Caregivers/Care Providers

• Many of the care providers have spent much of the patient’s adult life with them. They may feel more attached to the patient than you might expect.

• Within the home/facility there are many Interdisciplinary Team members who will all believe that they are the expert for and about the patient.

Recommendations for Visiting a Patient

• Always approach the patient from the front so that you are able to respond to the initial reaction from them.

• Talk to the people who know the patient best as any of the “responses” listed may not be indications of pain/discomfort but rather communication that he/she has used all of their life.

Possible Responses From the Patient

• Due to the ID diagnosis the patient may acknowledge your visit/presence in a variety of ways:
  ✓ quiet or loud vocalizations (even profanity might be a greeting);
  ✓ aggression (hit, kick, spit), smiles;
  ✓ reaching for you to hold hands,
  ✓ hug,
  ✓ roughly grab you;
  ✓ use sign language;
  ✓ or any number of other responses. . .
Interactions

• Meet the patient where he/she is.
• Please do not treat them as children as this will alienate them and their caregivers very quickly.
• These ID adults do not process things as we are able to but they understand much more when spoken to in adult tone of voice —— (i.e., while they love the song “Jesus Loves Me”, they probably wouldn’t recognize it if sung by the Chipmunks).

Reported Challenges by Hospice Providers

• Difficulty providing pain management due to patient’s inability to communicate discomfort
• Providing sufficient aide hours
• Having an able caregiver/ guardian problem because it may be an elderly parent who does not understand
• Guardians not understanding DNR and do-not-hospitalize orders

Challenges Reported in the Patient Homes

• Understanding death and dying, and that it is ok to talk about it
• Educating family members and guardians
• May be upsetting to other people who live with the patient
• Lack of information about community services
• Lack of in-home caregivers
Challenges Reported in the Patient Homes

- Support for staff; many are like family to long-term residents
- Coordinating hospice services with what the facility is able to provide
- Staffing ratios; human contact is critical
- Elderly parents may not be able to provide care

Myths

- They might be unable to think, reason, or verbally communicate.
- They do not understand death or dying.
- If they do not respond verbally or nonverbally to being told of the death, they will not grieve.

Important Things to Consider

- Each of these patients will be unique and precious in their own way.
- Most important, never be afraid to ask questions and enjoy the collaboration of expertise that this opportunity will open.
Important Things to Consider

• Providing end of life care for people who have Intellectual Disabilities will require us to have continuous education provided to us by those who provide services for them while we are educating them throughout the entire process.

Please allow them to appreciate you as they will be some of the most loving patients that you will ever have the opportunity to meet.

Anticipatory Grief & Providing Spiritual Support to ID Adults, their Families & Caregivers

• Description of anticipatory grief
• Providing spiritual support prior to death
• Challenges of providing spiritual support prior to death

Anticipatory Grief

Definitions of anticipatory grief
• “The emotional experience a person might have prior to losing someone of significance to him or her”. (Lindemann, 1944)
• “Any grief occurring prior to a loss as distinguished from the grief which occurs after a loss”. (Aldrich, 1974)
• “Anticipatory grief incorporates the processes of mourning, coping, interaction, planning and psychological reorganisation”. (Rando, 1986, 2000)
Emotional Components

- “The emotional components of anticipatory grief include sadness, anger, fear, distress, guilt, sorrow, despair, depression and relief”. (Raphael, 1984).
- Expression and intensity of the emotions vary from individual to individual.
- Emotions also are dependent upon individual circumstances.

Support Through Anticipatory Grief Reactions

- Validate the strong emotional bonds between the person with an intellectual disability and the family members or friends who are dying.
- Allow the person to visit and remain involved with terminally ill people if they wish to do so.
- Acknowledge and respond appropriately to their feelings.

Support Through Anticipatory Grief Reactions

- Give the ID person opportunities to come to terms with the reality of their impending losses.
- Help the person to think about possible changes in their lives and practical ways of dealing with the changes and loss.
- Allow the person to say goodbye and to communicate their farewells.
- This is a unique opportunity to provide support.
Providing Spiritual Support Prior to Death

- Begin by developing a trusting relationship with the person with intellectual disabilities, their family/guardian & caregivers
- Communicate with the person about death and dying and encourage them to express their feelings
- Acknowledge the genuine faith of the person, that they don’t fear death and that they are very much at peace – “Going to be with Jesus”

Providing Spiritual Support Prior to Death

- Share scripture and music
- Use books for stories
- Frequent contact with family/guardian and visit in person
- Provide opportunities for family/guardian to express their feelings regarding the person’s decline and approaching death

Providing Spiritual Support Prior to Death

- Very important to recognize the close relationships that exist with the ID person’s friends and caregivers
- Provide opportunities for the person’s friends and caregivers to tell them good-bye
- Your compassion, genuine concern and how you made them feel will be what the family/guardian and caregivers remember most and for the longest time
Challenges of Providing Spiritual Support Prior to Death

- Challenges with the person with intellectual disabilities are minimal.
- The biggest challenge is when the person is hearing impaired.
- Using a communication book or sign language are the best tools to enable the person to express him/herself.

Challenges of Providing Spiritual Support Prior to Death

Challenges with family/guardian & caregivers
- May have difficulty accepting the decline of the person and fact that the person is going to die
- Grieving loss of the person and change in their life as a caregiver because they have cared for the person so long
- Family/guardian is grieving the loss of the relationship they have with the caregivers

Benefits of Spiritual Support

- Allows the ID person, their family/guardian and caregivers to process the loss prior to the death
- Helps individuals discuss their feelings and beliefs about death
- Provides spiritual support, such as prayer, communion, music, spiritual conversation, and fellowship which often brings a sense of peace
- Builds the bridge for bereavement services
Providing Bereavement Support to Adults with Intellectual Disabilities, their Families & Caregivers

- Natural and normal grief at the time of death
- Coping strategies for adults with intellectual disabilities, their families & caregivers
- Types of bereavement support provided by hospice and the benefits

Natural and Normal Grief

- Medical advances have increased the longevity of persons with intellectual disabilities.
- Many live in the community in group homes, with family members, in special assisted living facilities or on their own.
- These changes have increased their attachments to a variety of people --- parents, guardians, friends, caregivers, staff members, co-workers in a workshop environment, members of their faith community.

Natural and Normal Grief

- One of the prices of these changes and variety of attachments is that the person with intellectual disabilities experiences loss . . . and they experience grief.
- ID persons generally grieve like we do when experiencing a loss.
- They will experience physical, cognitive, emotional, behavioral, and spiritual manifestations of grief.
Natural and Normal Grief

• Physical - Emotions displayed as physical symptoms, such as nausea, headache, body aches & pains
• Cognitive - Initial reactions of shock, disbelief or denial displayed as difficulty processing information, impaired concentration/judgment
• Emotional - Limited understanding of the death can result in displays of anger, guilt, jealousy, anxiety, sadness, regret

Natural and Normal Grief

• Behavioral - May behave in uncharacteristic ways, such as lethargy, hyperactivity, sleeping or eating pattern changes, withdrawal, acting out, resistance to change, compulsive behaviors
• Spiritual – May struggle with their faith, vent their anger at God, feel that the death was a punishment for sin
• As with all bereaved, there is no timetable to grief.

Coping Strategies for ID Adults, Families & Caregivers

• Disenfranchised grief – “situations where an individual experiences a loss but that loss is not openly acknowledged, socially supported, or openly mourned.” (Doka, 2002).
• Reasons –
  ✓ Caregivers may feel inadequate addressing needs
  ✓ Sense of over-protectiveness
  ✓ Feeling that the person doesn’t understand death or experience grief
Coping Strategies for ID Adults, Families & Caregivers

• If possible, begin to assist ID persons, their families and caregivers to cope with loss at the onset of the illness
• Answer questions honestly and provide support
• Allow the ID person to choose how they want to be involved – Do they want to visit/how often?
• Respect the ID person’s choice to avoid or deny the illness

Coping Strategies for ID Adults, Families & Caregivers

• A question that often arises – Should the ID person attend the funeral?
• Explain what the funeral will be like in words the person can understand
• Respect the ID person’s choice to attend or not
• Provide support to the person, family/guardian, caregivers before, during and after the funeral

Hospice Bereavement Support

• CMS Medicare Hospice regulations require that bereavement services must be offered for a minimum of 12 months following the death of a patient
• As with many patients, their families and caregivers, it may be helpful to provide pre-bereavement support
• Hospice Psych/Soc team (social worker, chaplain, bereavement coordinator) work together for pre-bereavement support
Hospice Bereavement Support

• Bereavement services of phone calls, visits, mailings, support groups, individual counseling and group counseling is offered by AseraCare for a minimum of 13 months

• Bereavement support provided to ID persons, their families & caregivers
  ✓ Memorial celebration held at the Region V workshop
  ✓ Individual counseling with ID persons & their caregivers at Region V
  ✓ More frequent contact with families and guardians

Hospice Bereavement Support

• Benefits
  ✓ Memorial events provide the opportunity to celebrate the person with intellectual disabilities in a meaningful way
  ✓ Individual counseling with ID persons and their caregivers enables them to express their emotions, feelings and beliefs in a non-judgmental setting
  ✓ More frequent contact with families and guardians provides an avenue for them to work through their feelings of loss and grief
Resources


