



Grief Work & Palliative Care Principles in Developmental Disability

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Objectives

- ▶ To review the definition and guiding principles of palliative care
- ▶ To identify the different kinds of grief and the importance of grief work
- ▶ To reflect on the grieving experienced by those living with developmental disabilities their families and caregivers

Palliative Care is...

- ▶ An approach that improves the quality of life for patients and families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of



- ▶ Pain +
- ▶ Physical
- ▶ Psychosocial
- ▶ Spiritual

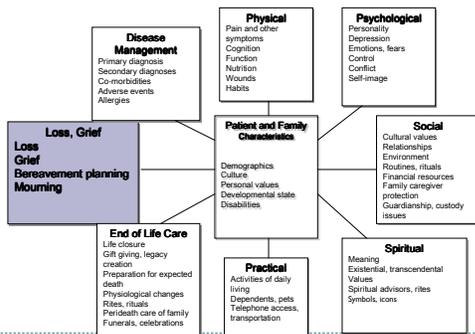
WHO 2010

Palliative Care Guiding Principles

- ▶ Person and family focused
- ▶ High quality
- ▶ Safe and effective
- ▶ Accessible
- ▶ Adequately resourced
- ▶ Collaborative
- ▶ Knowledge based
- ▶ Advocacy based
- ▶ Research based



Domains of Issues in Hospice Palliative Care



What is your definition of grief?

“He that conceals his grief finds no remedy for it”



Turkish Proverb



- ▶ Deep mental anguish, as that arising from bereavement.
- ▶ Something that causes keen distress or suffering
- ▶ Grief is the normal response to a loss.
- ▶ The normal process of reacting both internally and externally to the perception of loss

The psychological, behavioural, social and physical reactions to the loss of something or someone that is closely tied to a person's identity

Major Loss:

- ▶ Any loss experience that destroys a major piece of what makes our lives normal
- ▶ Our perception of the losses we experience is far more important than the circumstances of those losses.

Life after Loss (Deits; 2009)

Commonly Used Terms

- ▶ Bereavement is the loss (due to death)
- ▶ Grief is the response to the loss
- ▶ Mourning is the social expression of grief including rituals and behaviours specific to a culture and/or religion

Grief comes to every life.



What do we grieve?

- ▶ Death
- ▶ Divorce
- ▶ Loss of employment
- ▶ Loss of body image
- ▶ Illness
- ▶ A move to another city
- ▶ Many more...



Even minor or less significant losses will remain with you and may combine at some point to affect you “out of the blue”. You may over react to an apparently trivial incident; be irritable; have difficulty sleeping.

Life after Loss (Deits; 2009)

Classification of Grief

Normal

- ▶ Anticipatory
- ▶ Acute

Abnormal/Complicated

- ▶ Chronic
- ▶ Delayed
- ▶ Exaggerated
- ▶ Masked
- ▶ Prolonged
- ▶ Disenfranchised

LEAP

Define Normal



“Normal” Grief

Physical

- ▶ Hollow feeling in the stomach; tightness in the chest; heart palpitations etc.

Emotional

- ▶ Numbness; sadness; fear; anger; guilt; relief; etc.

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“Normal” Grief

Cognitive

- ▶ Disbelief; confusion; inability to concentrate; etc.

Spiritual

- ▶ Anger at or questioning core beliefs/God; re-evaluation of faith; searching for meaning; etc.

Risk Factors for Complicated Grief

- ▶ Relationship to the individual/meaning of the loss
- ▶ Nature of the relationship i.e., ambivalent, dependent
- ▶ Mode of loss or death i.e., sudden, violent, suicide
- ▶ Multiple losses
- ▶ History of psychiatric illness or coping difficulties

LEAP

Risk Factors cont'd

- ▶ Personality variables
- ▶ Lack of social support (perceived or real)
- ▶ Losses resulting in major changes
 - negative financial changes
 - loss of role
- ▶ Poor response to previous losses
- ▶ Elderly male widower
- ▶ Caring for the deceased over a long time

LEAP

The Four Tasks of Grief

Worden (1978)

- Task 1:** Accept the reality of the loss.
Move from denial of death and avoidance to recognition of the loss

How you can help:

- ▶ Accept grievers in their denial of their loss
 - * "It's hard to believe"
- ▶ Accept how difficult it is for them to accept the loss
 - * "It doesn't seem possible" "It is really hard"
- ▶ Encourage grievers to talk about their experience of the loss....then LISTEN!

What is not helpful:

- ▶ Rushing in to insist that the person accept reality
- ▶ Supporting false hopes and misconceptions

The Four Tasks of Grief

Worden (1978)

- Task 2:** Experience the pain of the loss.

How you can help:

- ▶ Act in a relaxed and accepting way
- ▶ Say the name of the deceased person
- ▶ Reassure that their grieving is normal
- ▶ Encourage ``small steps`` forward

* *The suffering associated with a loss is not a destructive process but a transformative one.*

What is not helpful:

- ▶ Rushing griever through the process; suggesting that they "snap out of it"
- ▶ Trying to make light of feelings of anger or guilt expressed by the griever. These feelings are often part of the normal grieving process



The Four Tasks of Grief

Worden (1978)

Task 3: Adjust to the new environment where the deceased is missing

What is happening at this stage?

- ▶ Exhaustion
- ▶ Preoccupation with feelings of loss
- ▶ Shame – relief that the person has died
- ▶ Life lacks lustre
- ▶ Loneliness

How you can help:

- ▶ Keep in touch: call, send notes, drop by (if that is consistent with your relationship to the bereaved)
- ▶ Repeat invitations even when previous ones have been refused



The Four Tasks of Grief

Worden (1978)

Task 4: Withdraw emotional energy from the death and invest in new relationships and activities

What may be happening at this stage?

- ▶ Enjoyment comes back into the griever's life; they may enjoy being alone and may feel freer
- ▶ Fear of dishonouring the dead
- ▶ Fear of experiencing the pain of another loss

How can you help?

- ▶ Acknowledge and validate feelings
- ▶ Do not judge!
- ▶ Gently encourage joining groups, taking courses etc.
- ▶ Never be too glib by using terms such as "Merry Widow" or "Eligible Bachelor"

People with Developmental Disability



- ▶ People with Intellectual Disabilities may experience their first loss in the perception by others of their value.....

Terminology

- ▶ What terms do you use?

- ▶ Developmental Disabilities
- ▶ Intellectual Disability
- ▶ Developmentally Disabled
- ▶ Learning Disabilities



WE need answers

- ▶ *Who will take care of me?* Include the Guardian in all the planning
 - ▶ *Where shall I live?* Allow the individual to have input into care directives
 - ▶ *When will he come back?* Loss: pets, plants, environment
- Frequent repetitions

Stress is a response to change

- ▶ A demand made on mental and physical energy
- ▶ Think of the changes that a person with developmental disability experience over their life time



Changes

Losses

- ▶ Home and Loved Ones
- ▶ Facility
- ▶ Room mate
- ▶ House mates
- ▶ Caregivers
- ▶ Teachers
- ▶ Volunteers
- ▶ Staff

Behaviours

- ▶ Crying spells
- ▶ Increased irritability
- ▶ Withdrawal
- ▶ Apathy
- ▶ Sleep disturbances
- ▶ Appetite changes
- ▶ Developmental regression

Many individuals
with cognitive impairments
deal best with
concrete rather than *abstract*
learning.

▶ Claire Lavin, Helping Individuals with Developmental Disabilities

Mindfulness

Self-awareness on the part
of the *caregiver* is the first
step towards being able to
help others

Caregiver Interactions to Assist in Grieving

- ▶ Acknowledge feelings
- ▶ Be real
- ▶ Participate in rituals
- ▶ Media recollections
- ▶ Religious Rituals
- ▶ Spiritual Beliefs
- ▶ Recognize severe reactions
- ▶ Fill the space
- ▶ ADVOCATE

Example 1

- ▶ James
- ▶ 36 years old
- ▶ Moderate Developmentally Delayed
- ▶ Limited Vocabulary
- ▶ Moved: Home to supervised community living
- ▶ PE: Dx arrhythmia likely RT medication
- ▶ Behaviours escalated beyond expected level of concern
- ▶ Grandmother died of HA 2yrs prior
- ▶ Unhealthy grieving process
- ▶ Education, Reassurance, Celebration of GM life

Example 2

- ▶ Sabrina
- ▶ 46 years old
- ▶ Mild intellectual disability with good vocabulary
- ▶ Lives in community home with several others with ID
- ▶ Mother disabled, raised by grandparents
- ▶ GM died 3 years ago, she was not involved in funeral
- ▶ Difficulty with relationships in the home
- ▶ Decision to relocate to another facility
- ▶ Behaviours escalated
- ▶ Unrecognized symptoms of unresolved grief



"All health care professionals are wounded healers.

They cannot escape suffering themselves.

Moments of pain, loneliness, fatigue and sacrifice are intrinsic to the human condition.

The physician or nurse's own suffering can become the source of compassion in the healer's art."

Sulmasy, D.P. (1997) *The Healer's Calling*

Questions or Comments?



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