

Supporting Adults with Intellectual Disability Through Bereavement and the Grief Process

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PURPOSE

- To assist in training of caregivers who directly support persons with intellectual disabilities, upon bereavement
- To introduce the concepts of loss associated with death through education, reflection, discussion, resources, strategies and case scenario

GOALS

- To enable caregivers in recognizing their own journey through grief and loss. In so doing, they may become better equipped to help others, both personally and professionally.
- To educate caregivers of adults with intellectual disabilities about the nature of the grief and bereavement process.₂

LOSS Appears in all Forms

- Loss of someone or something valued
- Loss of a familiar environment, such as the home or workplace, educational setting, institutional living space
- Loss of health – physical or mental, regardless of cause
- Loss of a partner in separation or divorce
- Loss of skill set, function, ability to produce or to achieve: a person with a terminal illness, in palliative care or in critical care gradually loses capabilities
- Loss of relationship with familiar caregiver, peer, family member

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1. WORD DISTINCTIONS

Bereavement

- a deprivation
- loss due to a death
- includes the period of time that it takes for the process of grief and mourning to take place and for the griever to heal from the pain and sorrow of loss

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Peripheral Loss

After a death, there may be additional losses that a bereaved person experiences.

Examples:

- Loss of self and life as once perceived
- Loss of personal or professional identity
- Loss of income, security and other resources
- Loss of the home place due to relocation after the death
- Loss of family, friends, peers who don't seem to understand what the bereavement process is for the griever ("they just don't get it")
- Loss of support network, staff member, significant roommate, social contact

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Grief

- the emotional response to the loss, i.e. the feelings which are experienced
- the pain or hurt which is felt
- a process which affects the individual physically, psychologically, intellectually, spiritually and behaviourally

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Grief (cont'd)

- unique to the individual's experience
- requires self-care to heal the pain
- this experience is considered to be normal and natural to any loss
- analogous to a wound which must heal from the inside to the outside

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Mourning

- the outward expression of a person's grief (Ex: crying)
- the external behavioural response
- "grief gone public" (Wolfelt) Ex: obituary
- cultural, religious, or personal rituals carried out in every society in order to assist with the grief expression and to give meaning to the loss

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2. TASKS OF MOURNING

(by William Worden)

Four Tasks:

- Acknowledge the reality of the death.
- Experience the pain.
- Adjust to an environment without the deceased
- Reinvest emotional energy into something new.

***There are no stages. There is no order.**

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Task: Acknowledge the Reality of the Death Loss

- transition from initial awareness and disbelief toward a full realization that the deceased is gone and will never return
- may take several weeks
- elucidates the functionality of funerals, memorial plans and rites

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Task: Acknowledge the reality of the Death Loss

Griever's Need for this task:

- to communicate about the events relating to the loss (Ex: picture books, picture symbols, words, sounds, scents)
- to remember deceased in life
- talk and dialogue give words to sorrow and sadness
- some survivors need information about the death while others do not want the details

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Task: Experience the Pain

- emotional, psychological, physical, behavioural response which is expressed internally and/or externally, known as grieving
- the expression of the pain is variable but unavoidable in order to resolve the issues and to heal
- North American society shortcuts this task
- most people are uncomfortable with their own grief experience and/or with expressing it in public or to other loved ones

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Task: Experience the Pain

Griever's Need for this Task:

- To work through the pain, to acknowledge it, go through it, feel it
- To know that undesirable behaviour and/or other symptoms reflect the manifestation of the avoidance of grief work
- caregiver(s), friend(s), family, or people who can encourage one to safely identify his/her feelings and to express them, i.e. listen, normalize, and give permission to feel whatever is felt or to state other losses (peripheral ones) associated with the deceased
- not to be judged negatively for experiencing certain feelings i.e. a feeling is a feeling, crying is not falling apart

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Task: Adjust to an Environment Where Loved One is Missing

- varies according to the relationship between the survivor and the deceased
- affected by the roles played by the deceased and the role losses/gains of the survivor
- again, society expects a quick recovery - in reality, the months ensuing the loss can be very difficult
- survivors can get stuck, especially by avoiding the learning of new roles/skills (Ex: deceased spouse took care of finances)

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Task: Adjust to an Environment Where Loved One is Missing

Griever's Need for this Task:

- support from caregiver(s) or friend(s) or other family in dealing with the reality of what has changed about life in day-to-day terms
- supportive people who can help to problem solve, to discourage major life-altering decisions
- to be encouraged toward new skills development, eg. financial management
- affirmation of accomplishments no matter how small or big

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Task: Reinvest Emotional Energy into Something New

- take the energy which was expended from the loss, the pain and the adaptation and put it into other activities and relationships
- the sense of moving forward in everyday life routines and events without the loved one in it
- ambivalent feelings of “push & pull” often experienced by the survivor with this task
- survivors “get stuck” here for a variety of reasons (Ex: fear of forgetting or dishonouring the loved one, feeling the deceased is replaced rather than understanding that a void is simply being filled)

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Task: Reinvest Emotional Energy into Something New

Griever’s Need for this Task:

- encouragement from others to explore issues of personal growth, the meaning and conceptualization of the loss, and spiritual issues
- to examine and assess the balance for self-care and care for others
- permission to experience deeper personal freedom
- freedom to explore new interests, goals, projects, and attachments

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TASKS OF MOURNING

SUMMARY of Needs for the newly bereaved person:

- Balance between aloneness and togetherness
- Opportunity to express feelings without embarrassment, i.e. Permission
- Information about normal reactions, i.e. Normalize
- Social support where there is trust, i.e. Presence
- Focus on the task, and not feel guilt for doing so
- Practical assistance, i.e. child care, financial, physical needs

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Reconciliation Needs of Mourning

(By Alan Wolfelt)

- Acknowledging the reality of the death.
- Embracing the pain of the loss.
- Remembering the person who died.
- Developing a new self-identity.
- Searching for meaning.
- Receiving ongoing support from others.

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3. When is Mourning/Grieving Completed?

- like asking how high is "up"?
- may or may not be a long term process
- dependent upon several factors
- variable time frames - seldom <1 year with close relationships
- may be from 2 to 5 years, w/traumatic losses
- triggers such as dates, events, and new losses can cause the pain and discomfort of grief to resurface

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Helping Yourself Heal When a Loved One Dies

(By Alan Wolfelt)

- Develop a support system.
- Make use of ritual.
- Embrace your spirituality.
- Allow a search for meaning.
- Treasure your memories.
- Move toward your grief and heal.

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We Must Do Our Own Grief Work

- It takes time, not a specified amount of time, but it's what we do with the time that helps us heal.
- Like a healed wound, a scar remains, but we move forward with living and loving again.
- Life will never quite be the same as it was before the death.
- With care and opportunity for enlightenment, we embrace the world again without our loved one.

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The Dynamics of Grief

- Each individual will have a unique timetable and style in which to process the pain. The depth and duration of the process will also be different.
- There is no formula for how much a loss will hurt or for how long it will last.
- If the natural response to loss is allowed to be expressed, it will promote healing and growth.
- Grief feelings may be measured in terms of intensity, duration and frequency.

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Factors Affecting The Grief Process

- Social
- Emotional
- Physical
- Intellectual
- Spiritual
- Psychological
- Financial

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4. Variables Affecting the Grief Process and Dynamics

Age

- every age group from infancy to the elderly grieves, i.e., it is a universal human experience

Gender

- each culture has its own stereotypes as to how men and women may or may not experience the grief

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Nature of the Relationship to the Deceased

- the bond, the closeness, the connection, the attachment or detachment
- what the loss means to the individual
- roles which are lost
- new roles which have been assumed

Nature of the Death

- sudden or expected, palliative or medical mismanagement, traumatic
- time expended or experienced prior to the death (Ex: long term illness)
- information provision by medical, legal or police or other personnel
- manner in which informed of the death
- cause of death (Ex: homicide, suicide, miscarriage, accident, unsolved or unknown)

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Preparation for the Death

- time to express certain thoughts and feelings (Ex: goodbye, ask or give forgiveness)

Individual Personality

- introversion/extroversion continuum preference type
- nature of perception & of decision-making functions
- lifestyle attitude

Life Experiences

- history of dealing with other losses
- experience with other deaths

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Health Status

- good vs poor physical health
- self-care practices
- presence of medical conditions, disease, illness or chronic pain prior & post death event
- Mental health, emotional well being

Coping Skills

- history of stress management skills
- history of ability to adjust to change, adapt to a new environment

Cultural and/or Religious Background

- expected rituals and expectations in private and in public
- nature of support of the individual's faith group

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Support Systems

- friends, family, community support/caregivers – the quality or lack thereof has impact
- reconfiguration of family or home environment (Ex: relocation, remarriage)
- communications, myths & attitudes about death & loss
- employment regulations - most allow 3 to 5 days bereavement period off work at the time of death, but specific to prescribed relationships

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Financial Resources

- medical, legal, funeral bills
- the Will - its execution, contestation, griever may be executrix/executor
- insurance coverage
- death notifications
- change in income range

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5. The Grief Process

The Experience: Common Physical Reactions and Responses:

- Deep sighing
- Weakness & fatigue
- Rapid heartbeat or palpitations
- Elevated blood pressure
- Increase in activity - hyperactivity
- Decrease in activity - lethargy

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The Grief Process

The Physical Experience (cont'd):

- Muscular tension
- Sleep disturbances - too much or not enough sleep
- Dreams
- Nightmares
- Decreased resistance to illness
- Weight and appetite change
- Increased sensory awareness

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The Grief Process

The Physical Experience (cont'd):

- Neglect of self
- Somatic disturbances (Ex: stomach-ache, headache, nausea)
- Dizziness
- Tingling
- Crying

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The Grief Process

Behavioural Responses:

- Crying
- Searching for what was lost
- Detached from surroundings
- Disoriented to time and place
- Withdrawn from friends & activities
- Unable to concentrate
- Forgetfulness
- Blameful of others or self
- Apathy

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The Grief Process

Behavioural Responses (cont'd):

- Preoccupation/day dreaming
- Seeking solitude (Ex: isolation/non-responsiveness)
- Seeking accompaniment
- Finishing "unfinished business"
- Seeking and providing forgiveness
- Spontaneity
- Increase in self-care activities
- Procrastination
- Frequent burial site visits

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The Grief Process

Emotional Responses:

- Numbness
- Confusion
- Euphoria
- Sadness
- Guilt
- Yearning
- Despair
- Hopelessness
- Hatred
- Helplessness
- Feeling of being lost
- Anger
- Suicidal feelings
- Bitterness
- Vengefulness
- Peacefulness
- Spiritual connectedness
- Fears - of any possibility

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The Grief Process

Cognitive - Intellectual Reactions:

- Impaired self-esteem
- Impaired ability to concentrate or comprehend
- Confusion
- Disbelief
- Denial
- Avoiding reality of the loss
- Repeated review or rumination of the loss event

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The Grief Process

Cognitive – Intellectual Reactions (cont'd):

- Increase or decrease of dreams
- Suicidal thoughts
- A search to understand the implications of the loss
- Practical problem-solving
- Creative activities
- Wisdom - personal growth, insight, enlightenment

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The Grief Process

Psychological Reactions:

- Depression (clinical)
- Anxiety, uncharacteristic mood fluctuations/ mood instability (clinical)
- Denial
- Bizarre (psychotic) behaviour
- Crazy feelings within (Ex: self-injurious behaviour/ aggression, destruction to property)

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The Grief Process

Spiritual Reactions:

- Praying, meditating, journaling, drawing, painting, dancing, singing
- Emptiness
- Challenge of beliefs or reason to live
- Change in ideals and beliefs
- Search for meaningfulness of life and connectedness

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The Grief Process

Spiritual Reactions (cont'd):

- Pessimism
- Idealism
- Acceptance
- Forgiveness
- Experiences of connectedness/wholeness/rebirth
- Compassion

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6. Disenfranchised Grief

Definition:

... those situations in which the larger society does not socially sanction and/or recognize certain bereaved persons' "right, role, or capacity to grieve"

(Doka1987, 1989)

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Various Sources of Lack of Recognition (cont'd)

- Certain relationships are not recognized as being acceptable within the existing societal context (Klein & Fletcher, 1986).

Example: homosexual or extramarital relationship

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Various Sources of Lack of Recognition (cont'd)

- Assumptions that a relationship has already been severed before the death.

Example: death of a divorced marital partner, death of a former in-law, death of one who long ago left home/has not kept in touch, death of incarcerated person or street person)

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Various Sources of Lack of Recognition (cont'd)

- Larger society does not understand that a significant loss has actually taken place

Example: miscarriage, stillbirth, death of a friend/colleague/ caregiver, death of a pet, elective or therapeutic abortion, neonatal death, SIDS death, failed IVF implantation, missing children

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Various Sources of Lack of Recognition (cont'd)

- Element of a stigmatized death or religious implications (Ex: suicide, death due to AIDS, HIV, hepatitis, cirrhosis of the liver, STD)
- Lesser value placement upon various groups of people - by diminishing their value as people, as such, we sometimes diminish their grief experience (Rando, 1992). (Ex: people with intellectual disability, people with emotional disability, lepers, prostitutes)

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Various Sources of Lack of Recognition (cont'd)

- Cultural assumptions that certain groups do not experience grief (Ex: babies, small children, the elderly and the infirmed, people with intellectual disability)
- Cultural expectations of individuals (Ex: gender and age, father of a stillborn/miscarried/aborted child)

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If the relationship is not recognized, then the loss is also not recognized. This results in a griever who is not recognized and is bereft of support.

Assumption

No relationship



Therefore, No loss



Thus, No Grief

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Outcomes for the Disenfranchised Griever

- Access to support systems is greatly diminished
- Probability of resolution greatly reduced
- Possibility of a great deal of shame or confusion about feeling the loss when others do not believe or recognize that it is significant

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Outcomes for the Disenfranchised Griever (cont'd)

- Feelings of guilt, shame, anger, embarrassment, loneliness, and isolation typically are felt more intensely (Oltjenbruins, 2000)
- The bereaved person is imprisoned by his/her grief reactions, thoughts and feelings
- Exclusion from the mourning rites prior to or post death
- Predisposition to complicated grief

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Scenario # 1: Joe

BEREAVEMENT (loss due to death)

- Loss of mom, who was an avid gardener

BACKGROUND

- 53 year-old male
- Bilingual – French spoken at home
- Mild ID
- Brothers (2); only had contact with Mom

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LIVING ARRANGEMENTS

Scenario #1: Joe

- Lived at home with Mom

EVENTS

- Found Mom and called 911
- Emergency placement in group home
- Moved 3 to 4 times before permanent placement
- Adjustment to different rules / expectations
- Difficulty with transition/ "fitting in"
- Referral for behavioural service due to uncooperative behaviour and foul language
- PCP completed; Joe expressed a desire to live with two female francophone roommates

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Scenario #1: Joe

LOSS of something valued while living (e.g. health)

- Gradual loss of vision

PERIPHERAL LOSS (additional losses after a death)

- Loss of natural family home
- Loss of/ diminished contact with brother
- Loss of familiarity with the rules / expectation of "home"
- Loss of personal identity (Francophone language/ culture, customs)

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Scenario #1: Joe

GRIEF (emotional response to loss/ feelings)

- Prefers to be alone and unwilling to attend work
- Sleep disturbances – up at night pacing
- Misplaced items – blames others for lost items, particularly items received from Mom
- Uncooperative, moody, foul language
- Reports "I feel like I have a hole in my chest."

MOURNING (outward expression of grief; behavioural response (cultural/ religious/ personal ritual)

- Textured flower pot from Mom; Joe had to know where it was located at all times, liked to have it close to him on his night stand
- Comforted in wearing ring that belonged to Mom

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Scenario #1: Joe

SUPPORT STRATEGIES

- Flower bouquet
- Tactile blanket
- Appropriate vocabulary
- Preferred support group

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Scenario # 2: Mario

BEREAVEMENT (loss due to death)

- Loss of mom, first
- Loss of Dad

BACKGROUND

- 50 year-old male
- English speaking
- Mild ID
- Diagnosed with cancer

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Scenario #2: Mario

LIVING ARRANGEMENTS

- Lived at home with parents, Mom died of cancer; with family support; Mario transitioned to larger facility
- Long weekends, summer vacations, holidays spent at home with Dad and extended family
- Visits less frequent as time progressed due to Dad's illness/ aging/ death; extended family contact continued via visits with Mario and phone calls
- When placement became available, moved to group home
- At group home, Mario lived with familiar peers and supported by familiar caregivers; was comfortable with move and called it "Home"

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EVENTS

- Mom/ Dad died of cancer
- Mario diagnosed with cancer; slow deterioration
- Receiving palliative care at permanent group home
- Referral for supportive counselling

LOSS

- Loss of health
- Loss of skill set as he deteriorated
- Loss of independence

PERIPHERAL LOSS

- Loss of natural family home

GRIEF

- Mario understood he was dying.
- Mario believed he was going to heaven.
- Mario believed he would join his parents; he was looking forward to it.

MOURNING

- Mario was obsessed with death and heaven.
- Mario repeatedly talked about his deceased parents who are now "angels."

SUPPORT STRATEGIES

Scenario #2: Mario

- Participated in Mom's and Dad's funeral services
- Elizabeth Kubler-Ross' materials used as resource
- Mario explored, with support, his beliefs and understanding of his feelings and experiences
- Mario discussed photographs and memories, significant relationships in his life, good times, others with illnesses, etc.
- Extended family contact maintained via visits (to natural family home occasionally and group home) and phone calls
- Support staff and Mario's natural family had a sense of connectedness in his support and care
- As he deteriorated, palliative care was provided at the group home

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In closing,

**GRIEF IS THE PUREST
EVIDENCE
THAT WE HAVE LOVED
AND LOVED WELL**

(anonymous)

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Other Resources

Grief Assessment Check List

Bereavement Assessment

Assessment Of Bereavement Recovery

Resources on Grief/ Bereavement for Children and Adolescents

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Questions



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