



# DEATH IN A NEW LIGHT

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# WHAT IS GRIEF?

The overwhelming emotion that occurs after the loss of someone or something consistent and/or important in a persons life.

There are many occurrences in life that may lead someone to grieve. These can include:

- Death of a loved one
- Moving away from one's family
- Separating from caretakers
- Changes/loss of staff

# TYPES OF GRIEF

## Anticipatory Grief

- Feelings of grief or loss that are felt before the loss actually happens.
- People facing their own death or the death of a loved one may experience anticipatory grief.

## Long Term Grief

- Grief that lasts longer than 6 months to a year
- Painful feelings of grief are long-lasting, severe, and lead to issues adjusting to the “new normal.”

# MISCONCEPTIONS ABOUT GRIEF

Grief gets smaller  
over time



# MISCONCEPTIONS ABOUT GRIEF



You need to be strong and handle grief alone

# CONSPIRACY OF SILENCE

People with IDD  
may not  
understand death

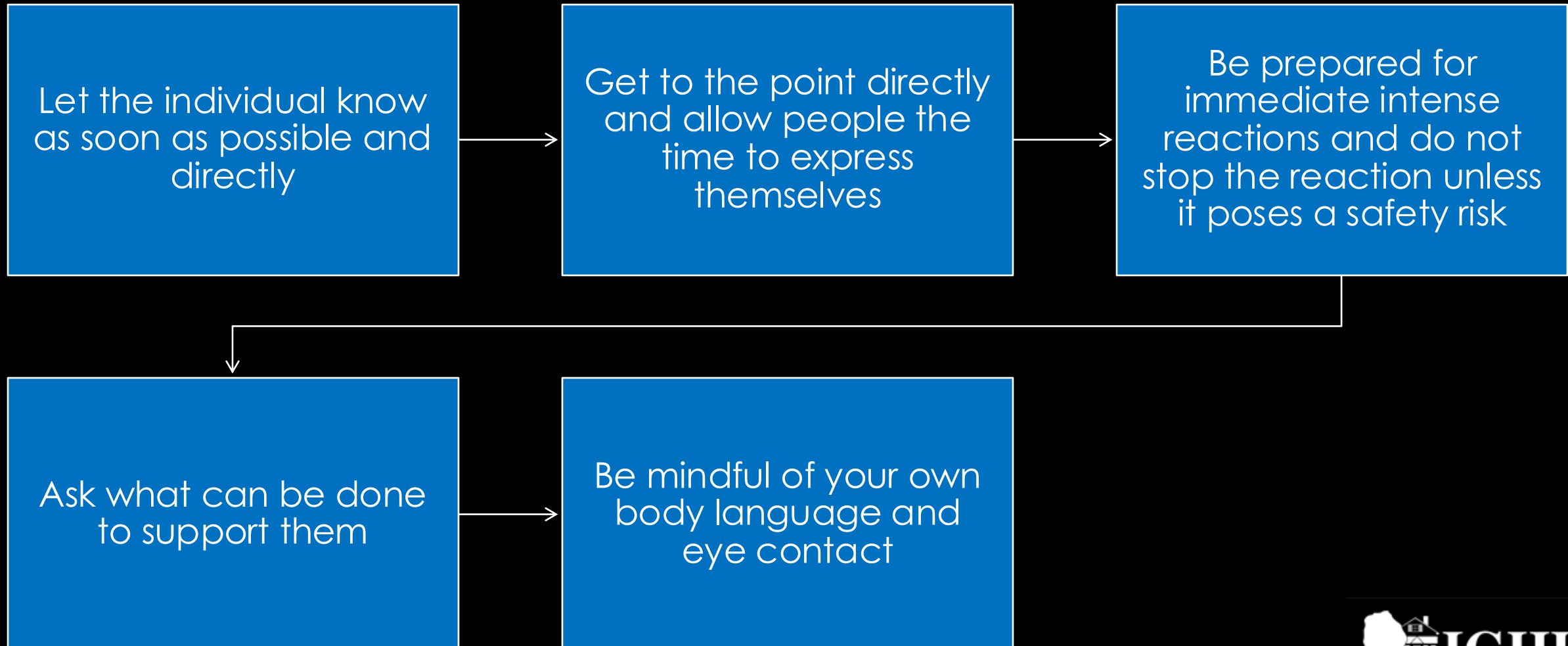
FALSE!

# CONSPIRACY OF SILENCE

People with  
IDD may  
not  
understand  
death

- Responses can be different
- Use Concrete Terms and Language

# WHEN DEATH OCCURS



# WHEN DEATH OCCURS: GRIEF TIMELINE

24-48 hours:  
impact of reality

5-7 days: mild  
depressive  
reaction

6-8 weeks: Most  
difficult time. Full  
impact of loss  
occurs.

3 months:  
irritability, acting  
out  
anger/frustration,  
crying, physical  
ailments

12-24 months:  
acceptance and  
resolution

2+ years: mild  
depression on  
special dates  
and holidays

# THE FOUR CONCEPTS OF DEATH

These four concepts can help us understand and cope with death. It can still be confusing for many people with varying degrees of intellectual ability.

- **Irreversibility**
- **Non-functionality**
- **Universality**
- **Causality**

# TASKS OF MOURNING

- **Task 1:** Accept the reality of the loss.
- **Task 2:** Process the pain of grief.
- **Task 3:** Adjust to a world without the deceased.
- **Task 4:** Find a way to remember the deceased while moving forward in life.

# DEVELOPMENTAL STAGES OF UNDERSTANDING DEATH

## Pre-School Level

- may be useful for persons diagnosed with profound or severe ID
  - Personal security and continuity
  - Not able to understand the 4 concepts of death
  - Difficulty self regulating when upset
  - Tuning into the environment
  - Participation in funeral or other traditional ceremonies

# DEVELOPMENTAL STAGES OF UNDERSTANDING DEATH

## School – Aged Level

- may be useful for persons diagnosed with severe or moderate ID
  - Has beginning knowledge of the 4 concepts of death
  - Fact oriented
  - Individual will not want to be singled out or the center of attention
  - May resist counseling or therapeutic intervention
  - May not emote immediately
  - Person should be given a choice in participating in the funeral

# DEVELOPMENTAL STAGES OF UNDERSTANDING DEATH

## Adolescent Level

- may be useful for persons diagnosed with moderate to mild ID
  - Has more in-depth knowledge of the 4 concepts of death
  - Person has the ability to empathize
  - Likely to question why it has occurred
  - May benefit from established boundaries for grief
  - May enjoy being the center of attention
  - May tell many people that someone has died
  - Person should be given the choice to participate in funeral

# DEVELOPMENTAL STAGES OF UNDERSTANDING DEATH

## Seniors

- may range in functioning level
  - Experience complex grief due to multiple losses
  - Unwilling to let others know they are sad or grieving
  - Issues may arise in counseling
  - Important not to recognize ageism and do not assume to know what someone is going through
  - Loss is more expected at this time in a persons life but an unexpected loss may be devastating. Seniors may also need more time to adjust to change.
  - More likely to result in physical illness or conditions
  - May experience loneliness more so compared to younger persons.

# WAYS TO HELP

**Make practical concrete suggestions about what can be done, do not offer ideas that sound nice but are impossible to complete.**

- Ask what would be helpful in the moment
- Group discussions or individual counseling
- Encourage participation in rituals surrounding death
- Encourage talking about feelings
- Use religion or spirituality according to the persons beliefs
- Expect some unusual behavior to occur

# ADDITIONAL WAYS TO HELP

- Cards
- Flowers
- Visiting or calling family/friends
- Bringing food
- Offer an act of service
- Make donations
- Rituals
- Memory books
- Poems/Songs
- Letter
- Photos/collages
- Plant a tree
- Blow bubbles
- Light a candle

# END OF LIFE PLANNING

Persons diagnosed with I/DD are living longer and having to experience the complexities of aging. Staff and families also struggle with these changes.

- Health Care Proxy vs Guardianship
- MOLST
- Hospice/Palliative Care Consults
- Burial Arrangements
  - Direct Cremation
  - Direct Burial/ Immediate Burial
  - Funeral Services

# HOW IGHL PROACTIVELY PREPARES FOR DEATH

- Discussions during intake and move-in process
- Meet with local funeral homes to understand what is needed for planning
- Outreach letters regarding future planning to all individuals living in residential programs
- Annual inservices about grief and death
- Open conversations to discuss fears/concern about grief and death

# HOW IGHL HANDLES DEATH IN THE MOMENT

- Trained counselor communicates the news
  - Try to do it individually first, then a group discussion
- Provide safe space and time for grieving and processing
- Creating a safe space for a memorial service that allows everyone an opportunity to express themselves through speech, song, or artwork
- Creating a Memorial Garden

# MEMORIAL GARDEN

Involving Community Members

Creating Individualized Rocks and General Rocks



Girl Scout Troop 662



Girl Scout Troop 3200



# QUESTIONS

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