## Grief and Loss for DSPs

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### What is a DSP?



#### What is a DSP?

- Coaches
- Advisors
- Medical Escorts
- Translators and interpreters
- Decision-making facilitators
- Counselors
- Advocates

- Mediators
- Financial Advisors
- Memory joggers
- Companions
- Vocational liaison
- Task Masters
- Transporters



#### Connection

- It's impossible to fill the role of a DSP without becoming connected to the people they support, really connected
- Strong emotional bonds occur over time and result in a significant and sincere investment in people



#### Connection

- The emotional connection and commitment is a two-way street!
- This connection results in the full spectrum of human emotions, including and experiences, including trust, joy, frustration, happiness, affection, and love
- It's the human connection that keeps many DSPs on the job



## The Uniqueness of DSPs

- DSPs rejoice in seeing new skills, independence, progress, and growth
- Also saddened by set-backs, failed attempts, program glitches, rejections, and unintended consequences
- Empathetic to health crisis, accidents, complicated co-existing medical conditions



#### DSPs and the Person-Centered Model

- This model of service puts the DSP in a circle with many other people that are part of the person's life
  - Family members
  - Friends
  - Roommates
  - Other Professionals
- Being the center of communication means communicating EVERYTHING, good and bad



#### DSPs and Grief

- Not a singular griever
- Because of the person-centered model, they must support and counsel others in times of grief and loss
- This support is often at the expense of their own ability to grieve
- Can make DSPs more susceptible to delayed, prolonged, or incomplete grieving



# Grief, Mourning and Bereavement



#### What is Grief?

- A natural reaction and internal experience to loss
- Grief is a strong, sometimes overwhelming emotion for people regardless of whether their sadness stems from a loved one, terminal diagnosis for themselves or others.
- The ability to grieve comes from our capacity to give and receive love
- We incorporate our feelings into everything we do, accepting how we feel. It's not something to 'get over'
- People can feel numb and removed from daily life, may feel they are unable to carry on



## Mourning

- Outward expression of grief
- Shared social response to loss
- 'Grief gone public'
- Can last months or years



#### Bereavement

- To be torn apart and have special needs to deal with your loss
- Feel we are in pieces, that there's a hole in our life
- Your needs have shifted, because of the loss
- Things are different in your life now, and it's hard to cope



## Stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance
- Some people may skip steps or experience them in a different sequence



## There's No "Right" Amount of Time

#### Can depend on

- Personality
- Age
- Beliefs
- Support Network
- Type of loss
- Sudden vs. expected



# Types of Grief



#### "Normal" Grief

- No set guidelines on timeliness /severity
- Any response that is what you think it should look like
- Gradual decrease in intensity of emotions over time
- Connected with emotions but can still function normally with daily activities



## Delayed Grief

- Reactions / emotions are postponed until later time
- May be initiated by another major life event or something that seems unrelated
- Reactions can be seen as excessive to the current situation
- Person may not realize they are experiencing this type of grief



#### Chronic Grief

- Feelings of hopelessness, sense of disbelief that the loss is real
- Avoiding situations reminding them of the loss
- Loss of meaning and value in their own belief system
- Intrusive thoughts- turns to severe clinical depression / substance abuse, self-harming thoughts and suicide



## Complicated Grief

- Also known as traumatic or prolonged grief
- Becomes severe in longevity and impairs the ability to function
- Warning signs
  - self-destructive behavior, deep persistent severe grief, low selfesteem, depression, suicidal thoughts, violent outbursts, radical lifestyle changes



## Exaggerated Grief

- Grief responses are intensified and considered beyond 'normal'
- Symptoms tend to get worse as time goes on
- Symptoms may include self-destructive behavior, drug abuse, unnormal fears, suicide ideation, nightmares, potential development of psychiatric disorders



#### Inhibited Grief

- Someone who doesn't outwardly show any signs of grief, or isn't allowing themselves to grieve
- Unconscious way to keep grief private
- Can have physical manifestations such as headaches, body aches, digestive issues



#### Masked Grief

- Inability of oneself to recognize the symptoms they are experiencing are connected to a loss
- Can manifest through physical symptoms or other negative behaviors that are out of character



## Absent grief

- No sign of grieving and the person is not acknowledging the loss
- Can be experiencing shock or denial of the loss
- Can be concerning if happens for extended period of time
- Just because you can't see signs of grief, doesn't mean they aren't grieving



## Cumulative grief

- Experience of multiple losses in a short period of time
- Don't have time to grieve one loss before the next
- Can cause feelings of being overwhelmed, sadness, depression, loss of purpose



#### Collective Grief

- A group of people who are grieving together over the same loss
- Group homes, communities
- Can include natural disasters, death of public figure, terrorist attacks
- Can be experienced by those working in a group setting such as a group home or day service



## **Anticipatory Grief**

- Starts before person passes away
- Can start when person gets a terminal diagnosis
- Loss of what used to be, or what life should have been like
- Difficult to talk about because person is still alive
- Feelings of guilt or confusion



#### Disenfranchised Grief

- Happens when others do not acknowledge the importance of the loss in the person's life
- Others may not know the significance of the loss or may minimize the significance of the loss to the person
- Common for DSPs due to the demands of their job who are expected to be professional
- The person is physically present but absent in other significant ways



## Symptoms of grief

- Grief can effect your entire being- Physically, socially, emotionally, spiritually
- Differs for each person and each situation depending on life experiences, relationships, other things going on in your life
- Culture, religion, social norms = what we show to others
- Important to understand typical and atypical grieving not only to support yourself, but to support people in services



## Physical Symptoms of Grief

- Crying
- Sighing
- Low energy
- Weakness
- fatigue/exhaustion
- Headaches
- Stomach aches
- Self-destructive activities

- Eating too much
- Loss of appetite
- Sleeping too much or too little
- Disturbing dreams
- Heaviness
- General aches and pains
- Trying to stay busy
- Pushing yourself too hard



## Social Symptoms of Grief

- Wanting to isolate, even though you may feel alone
- Finding it hard to pretend to feel ok and be social with others
- Feeling detached from others, not understanding or liking that their lives are continuing on while yours has been torn apart so much
- Feeling too needy, clingy



## **Emotional Symptoms of Grief**

- Crying or sadness
- Anger, frustration, rage
- Confusion
- Feeling overwhelmed
- Guilt
- Worry, anxiety, irritability,
- Memory problems, easily distracted
- Depression,
- Fluctuating emotions



## Spiritual Symptoms of Grief

- Questioning the meaning of life
- Questioning the meaning of suffering
- Asking WHY is had to happen
- Anger at god or a higher power
- Becoming closer to faith for solace.



# Grieving and the Realities of the System



#### We Have a Business to Run

- Empty bed- seen as lost revenue
- Waiting list causes pressure
- Organizations often move too quickly to replace the person who has passed
- DSPs are at odds with the system they work in, which often disrupts the grieving process



## How Organizations Respond Matters

- A fast turn-around is disruptive for the grieving process
- Sends a message of "It is what it is, move on"
- Sends a message that the people are commodities that can be replaced



## How Organizations Respond Matters

- Organizations that allow time for grieving communicate the message that DSPs are valued
- There must be a balance between business needs, the needs of grieving DSPs, and the needs of the people in services



## How Organizations Respond Matters

- Grieving is a natural, normal, and healthy response to loss. Anything that interferes with that process denies people the opportunity to participate in the journey of life
- DSPs can't be told to do their work with their heart and their mind,
   and then later be told they have to abandon their hearts



## Thank You!

