End of Life Care

Supporting Grief and Bereavement

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An agency of the Provincial Health Services Authority

Goals

- To develop a flexible teaching module for use in the renal population around grief and bereavement.
- To ensure highest quality support for patients and families in this topic area
- To ensure we know how to support each other in this area

Educational Objectives

- Understanding normal grief and how to support it
- Distinguish between normal grief and abnormal or complicated grief patterns
- Risk factors for complicated grief in this population , and what can we do?
- Case Studies & video
- Supporting each other and building this support into practice

Definitions

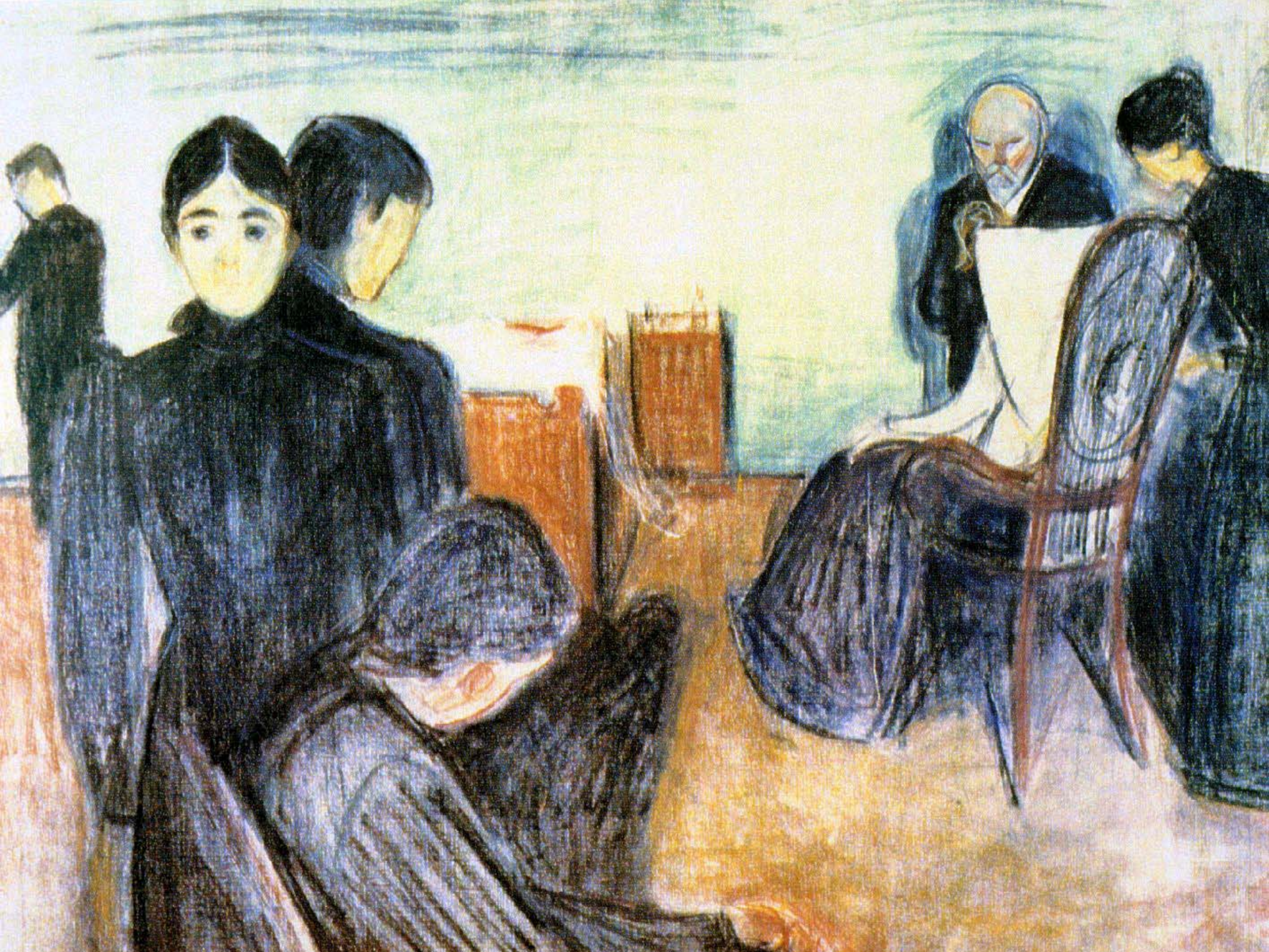
- Bereavement: the loss of a significant person and also the period of adjustment for the bereaved after the loss.
- Grief: the normal response to the loss of someone or something precious.
- Mourning: the social expression of grief after a death, associated with rituals and behaviours within the appropriate religious and cultural context

Classes of Grief

- Typical (Normal)
- Anticipatory
- Complicated
- Disenfranchised
- Unresolved

What are Your Family/ Cultural Traditions?

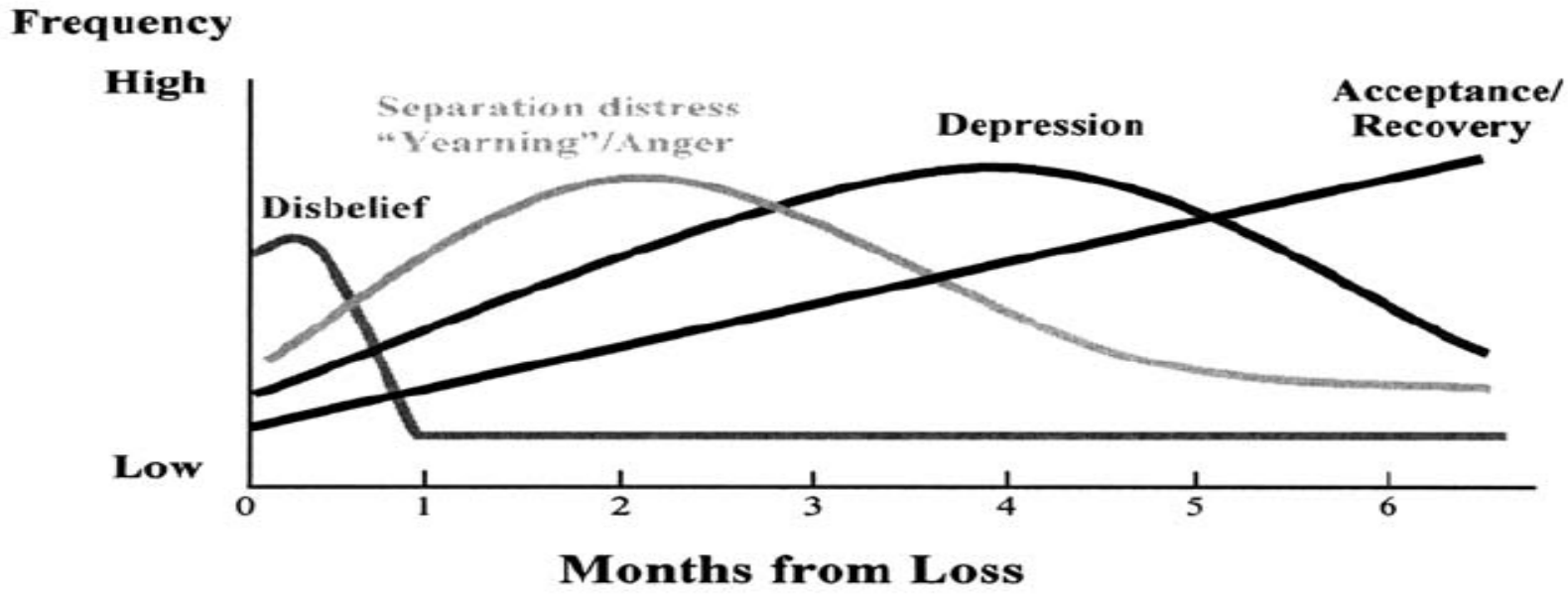
- Do you understand how they have developed over centuries?
- Are they important to you?
- Are they important to your siblings?
- Are they important to your children?
- What other traditions have you witnessed?



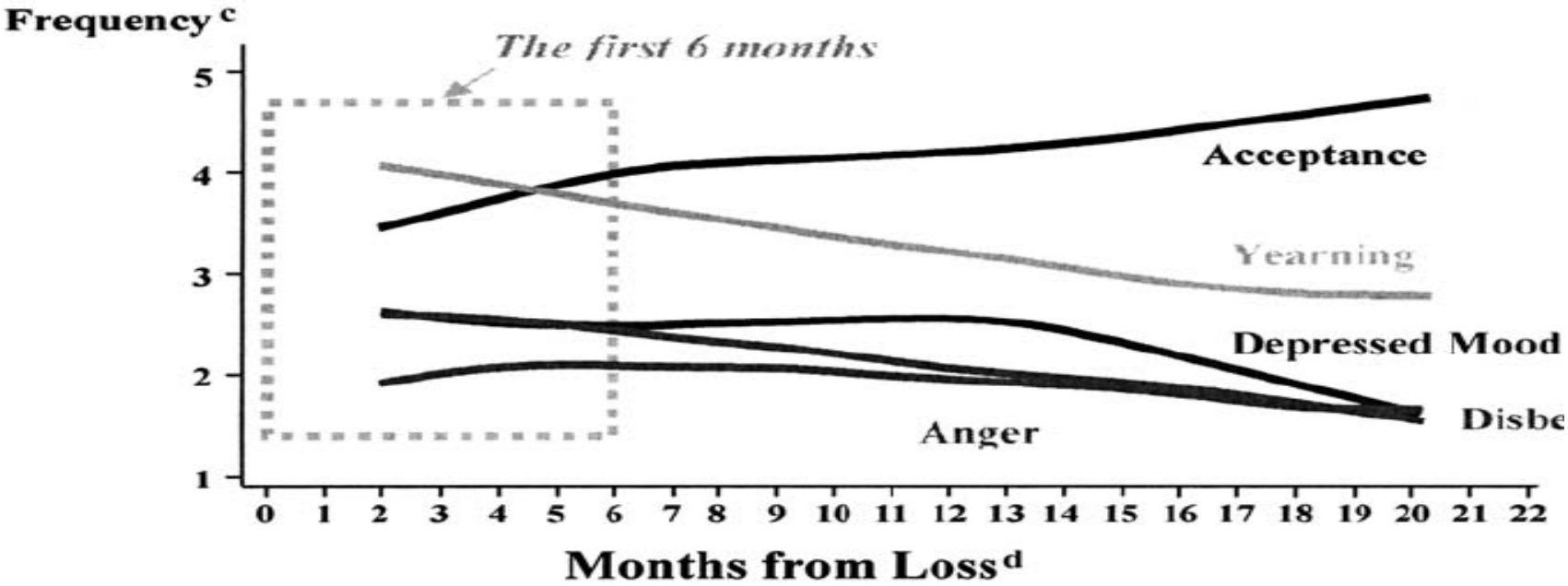
Understanding Normal Grief and How to Support It

- 85% of grief experiences follow a normal pathway – it's **not** about fixing it
- In the context of a death, grief is a complex lifelong process that involves transforming a relationship rather than detaching from it
- We all grieve differently- allow for diversity
- It often gets worse before it gets better.
- You can't prevent grief, but you can try to develop elements of **resilience**

Hypothesized Grief Resolution



Adjusted[a] Mean[b] Grief Resolution Scores Over Time



Resilience

"the capacity to bounce back, to withstand harm yourself"

- Insight
- Independence
- Relationships
- Initiative
- Creativity
- Humour
- Morality

Understanding Normal Grief and How to Support It

- Bad News - SPIKES
- Lifestyle Management
  - What is helpful for them
  - “Homework”
- Education
  - Normalize the process not “going crazy”
  - What to expect
  - What is helpful
  - Giving hope
  - Key phrases
  - Clichés to avoid
  - Resources
- Pharmacology

Key Phrases

- Use the deceased's name
- Acknowledge the death – "I am sorry Sam is gone"
- Talk about the deceased and memories, ask about "What are you remembering about Sam today?"
- Bring closure to the death "Do you have questions about Sam's final illness or treatment?"
- Talk about grief feelings: "How has Sam's death affected you?"

Key Phrases

- “I am sorry”
- “It must be hard for you”
- “What would be most useful right now?”
- “Do you want to talk about it?”
- “Do you have someone you would like me to call?”
- “What do you miss most about Sam?”
- “What would you like me to do for you?”
- “What are your supports?”

Clichés to avoid

- " I understand" or " It's for the best"
- "There was a reason" or " It's God's will"
- "I know how you feel"
- "Time heals"
- "You will get over it"
- Avoid giving examples of those who are "worse off"
- Disallowing patient's feelings " You should be getting over this by now"
- Giving early advice

Resources

- Every member of staff should know how to access
- Handouts / leaflets
- BC Bereavement Helpline & other counseling/ grief support resources
- Local Hospice Society
- Don’t forget the GP
- Specialist areas – children, teenagers, mental health

Case Study – Mrs Malkani

In “last lap” of illness

- Discussions, frequent and compassionate, with family about what to expect
- Specifically ask about how things are discussed/ decided in their family and if they need help
- Specifically ask how they are communicating with children/ grandchildren – do they need input?
- Give leaflets about Federal Compassionate Benefits & Provincial Palliative Benefits schemes
- Try to promote elements of resilience
- Check they have funeral plans/ who needs to be contacted

Case Study – Mrs Malkani

After death

- Breaking bad news – SPIKES
- Listen actively & give resources
- Almost everything is normal immediately
- Ensure they have complete practical information (this should have happened earlier, but check)
- Check about the children / teenagers
- Make sure they know how to /whom to call for any questions/ concerns/ help
- Send a card – signed by main caregivers
- Invite to a memorial later

VIDEO CLIP

Complicated Grief

- DSM V Criteria for “Complicated Grief Disorder
- Identifiable risk factors:
  - Childhood abuse and serious neglect
  - Past or current mental health/ depression/ substance abuse
  - Multiple losses
  - Sudden, traumatic, “preventable” death
  - Loss of a child
  - Social isolation & disenfranchised role
  - Prior angry/ ambivalent/ dependent relationship with deceased
  - Additional life stressors – money, job demands, children

Complicated Grief
Criteria Proposed for DSM - V

Criterion A Yearning, pining, longing for the deceased

Yearning must be experienced at least daily over the past month or to a distressing or disruptive degree

Criteria B In the past month the person must experience four of the following eight symptoms as marked, overwhelming, or extreme

1. Trouble accepting the death
2. Inability trusting others since the death
3. Excessive bitterness or anger about the death
4. feeling uneasy about moving on with one's life (e.g., difficulty forming new relationships)
5. feeling emotionally numb or detached from others since the death
6. feeling life is empty or meaningless without the deceased
7. feeling the future holds no meaning or prospect of fulfillment without the deceased
8. feeling agitated, jumpy or on edge since the death

Criterion C The above symptom disturbance causes marked dysfunction in social, occupational, or other important domains.

Criterion D The above symptom disturbance must last at least 6 months.

Complicated Grief

- What does it look like?
  - Difficulty moving on or re-engaging with life
  - Numbness/ detachment
  - Bitterness
  - Feelings that life is empty without the deceased
  - Trouble accepting the death
  - A sense that the future is meaningless
  - Being on edge or agitated
  - Difficulty trusting others, social withdrawal

Complicated Grief

- Need to recognize early because:
  - Symptoms of complicated grief post loss are highly predictive of impairment and complications at 13 and 24 months post loss
  - The rate of depression is 15-35% during the first year after loss of a spouse
  - Suicide risk especially after loss of a child, loss of a spouse (older men) and sudden traumatic loss
  - Higher rates of morbidity, mortality, health care utilization, alcohol, tobacco, sedatives and impaired immune function.

Complicated Grief

- Pre loss interventions:
  - Preparedness – ready to say “goodbyes”
  - Early enrollment in hospice care
- Post loss interventions:
  - Explore reasons for being unable to grieve
  - Review circumstances around the death, and the relationship
  - Psychotherapeutic
  - Pharmacologic

Grief vs Depression

Feeling	Grief	Depression
Mood states	Greater range, quick shifts in a day, variability in mood, activity, appetite,sexual interest in one week	Mood and feelings static-consistent sense of depletion,psychomotor retardation,anorexia,sexual interest
Anger	Open, externally directed	Absence of external anger, Internally directed
Sadness	weeping	Difficulty weeping or controlling weeping
Self concept	Guilt associated with specific aspects of the loss – preoccupation with loss - world seems empty	Loss confirms they are bad or un-worthy – punitive thoughts – global guilt. Preoccupation with self
Responsiveness	Periodic – want solitude but respond to warmth & involvement	Static – fear of being alone and yet unresponsiveness to others
Pleasure	Periodic – responds to warmth and involvement	All pleasure restricted – loss of sense of humour

Case Study – Paul Smith

Complicated Grief

- Patient himself
  - Multiple losses
  - Surviving spouse (less than 1 year)
  - Financial/ legal/ custody concerns
- Teenagers
  - Multiple losses
  - Multiple stressors
  - Changes/ secondary losses

Case Study – Paul Smith

Patient himself - What to do?

- Refer early
- Marshall resources/ information
- Advance care planning
- Guardianship issue
- Leaving a legacy – memory boxes & letters
- Pain and symptom management
- Surveillance for depression/ substance abuse

Case Study – Paul Smith

Teenagers – Before death What to do?

- Refer early – including school counselors
- Information and communication ASAP
- Respect and acknowledgement and confidentiality
- Information about grief
- Opportunities to express themselves
- Affirm and normalize
- Prepare for mourning rituals

Case Study – Paul Smith

Teenagers – After death What to do?

- Normalize the grief process
- Opportunities to “tell the story”
- Strategies to cope with change
- Allaying fears
- Contained remembering
- Importance of school
- When to worry

Care after Death

- **1.** Use a death/bereavement checklist that contains details of all the necessary steps
- the renal team must complete when a patient dies.
- **2.** Ensure that the surviving family/friends are aware of community supports for managing
- grief and bereavement in a healthy way. This includes information on local
- hospices, support groups and bereavement counseling services (local and national
- organizations).
- **3.** Consider ways to acknowledge the patient's death. This could include a notice in the
- waiting room, posting obituaries and/or placement of a ritual flower arrangement
- or card by the nursing station. Other options include a yearly memorial service, to
- which family and friends are invited.
- **4.** Consider sending the family a condolence card or letter of sympathy. Some units
- send families an anniversary of death card in the first year.
- **5.** Consider that it may be important for some of the renal staff to attend patients'
- funeral/memorial services.
- **6.** Create opportunities for staff to discuss and reflect upon recently deceased patients
- in a respectful non-judgmental environment.
- **7.** Ensure that staff is aware of bereavement and counseling services through employee
- assistance program.
- **8.** Look for opportunities to expand knowledge and expertise of staff through continuing
- education on death/dying topics.

Our Circle of Care

- Non – negotiable in this context of healthcare
- Team meetings not just technical reviews but remembering spaces
- Awareness of early “burnout”
- Awareness of staff supports available
- Memorials are for the staff as well

Recognizing Early Burnout….

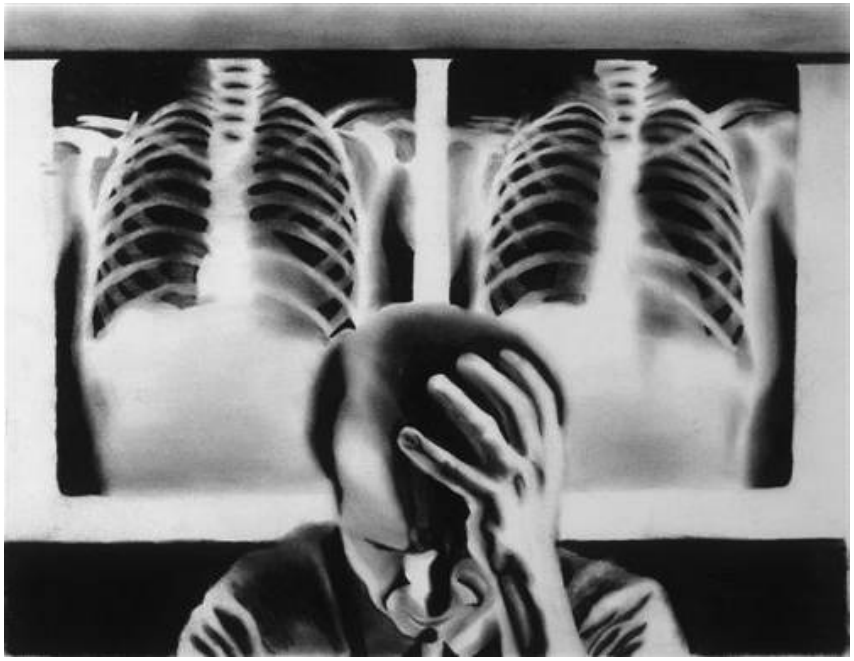
- Avoidance
- Blaming the patient / family
- Negative thinking / blocking
- Health issues
  - Days off sick
  - Substance abuse

……and What to Do

- Physical well being
- Professional relationships
- Transcendental
- Talking with others
- Hobbies
- Clinical variety
- Personal relationships
- Boundaries
- Time away
- Passion for work
- Realism
- Humour and laughter
- Remembering patients

Acknowledging Our Own Grief

- For individual patients
  - Individual "closure" rituals
  - Group "moment of silence" or reflection on what we learned from this person about death
  - Photos or characteristic items as transitions



Managing Many Losses

- Personal Strategies
- Make choices and Set Priorities
- Recommendations to Organizations
- Recommendations at Policy Levels

Acknowledging Our Own Grief

- For cumulative deaths
  - Personal philosophy of life, death, medicine
    - Certainty, control, responsibility
    - Emotional distance, flexibility, conflict
  - Resources for avoiding stress, burnout
    - Balance personal, professional life
  - Rewards for this aspect of medicine
    - Sense of connection, accomplishment, success