Impact of life-limiting conditions on patients and families

Understanding social, cultural and emotional needs
Aims

• To gain a better understanding of the impact life limiting illness has on patients and families on every level of human experience.
Ground rules

• Confidentiality
• Mutual respect
• Punctuality
• Self care
• No mobiles
Case Study

- Exercise in groups of 4 or 5
Culture

Sibling

Mum

Dad

Health

Sibling

Employment

Social relationships

Own family

Culture
Holistic Care

- Social
- Spiritual
- Psychological
- Physical
- Behavioural
Physical symptoms

• Pain
• Nausea/Diarrhoea/Constipation
• Sleep disturbances
• Breathing difficulties
• Mobility
• Fatigue
• Lack of coordination
• Cognitive impairment/speech
Psychological/emotional symptoms

Moodiness
Irritability
Depressed mood
Apathy
Guilt
Restlessness, excitability
Shock
Blaming
Hopelessness

Sadness, crying
Feeling lost, isolated, abandoned
Recurrent dreams
Insomnia
Frustration
Anxiety
Fear
Anger
Behavourial symptoms

Poor Concentration
Forgetfulness
Slowing thinking
Verbal expression
Disorientation
Over-activity

Loss of confidence
Eating more or less
Loss of work efficiency
Easily startled
Difficulty in making decisions
Social implications

Intentional social isolation
Relationship tensions
Reluctance to leave home
Frequent arguments
Alcohol /tobacco/drugs
Fear of being alone

Shortness with others’ concerns
Drifting away to own thoughts in conversation
Seeking out those in similar circumstances
Rejection of those in similar circumstances
Spiritual

- Intense spiritual search
- Rejection of previous beliefs and practices
- Anger at God
- Fear of judgement
- Doubts and modification of prior beliefs
- Questions about meaning of life
- Strict adherence to religious practices
Losses

• Employment / financial status/career
• Ability to go out
• Retirement
• Leisure time / Holidays
• Sexual life / intimacy
• Future dreams (see children grow, etc)
Loss, grief, bereavement and mourning
“The death of a loved one is not only a loss, it is a turning point; the world will never be the same again. Each bereaved person faces a long period of adjustment to a life which is seldom wanted or planned.” (Parkes, Relf and Couldrick, 96)"
Theories of Grief

• Tasks of Mourning – Worden
• Elizabeth Kübler-Ross
• Colin Murray-Parkes
• Dual Process – Stroebe & Schut
• Continuing Bonds – Klass
Tasks of mourning
William Worden (1982)

• Accept the reality
• To work through the pain
• To adjust to an environment without the dead person
• To emotionally relocate and memorialise the dead person

Worden/Silverman, 1996
Kübler-Ross

• Denial – Conscious or unconscious refusal to accept the fact
• Anger – (with others, God, guilt, shame)
• Bargaining – Attempt to bring person back (had I done this, if I do this...)
• Depression – Beginning to accept reality and preparation for acceptance
• Acceptance
Murray Parkes

• A period of numbness occurring close to the time of loss
• A phase of yearning: for lost one to return; a denial of the permanence
• Disorganization/despair; bereaved finds it difficult to function in environment.
• Reorganized behaviour...beginning to pull life back together.
Dual Process Theory

Stroebe & Schut 1995

Everyday life experience

Loss oriented
- Grief work
- Intrusion of grief
- Breaking bonds/ties
- Denial/avoidance of restoration changes

Restoration-oriented
- Attending to life changes
- Doing new things
- Distraction from grief
- Denial/avoidance of grief
- New roles/identity/relationships
Continuing Bonds
Klass (1996)

• Thinking about, memories of, talking about and talking to; wearing/carrying things which belonged to the person who died.
• Dreaming about them.
• Having a sense of their presence.
• Carrying out their wishes, adopting their values.
• Identifying with them (trying to be like them).
• Forming rituals and memorials – eg ‘On Mum’s birthday I always go to her favourite tea shop.’
Case study

• You are a 42 year old woman. You come from a supportive family. Both you parents had jobs they enjoyed and gave them satisfaction. Your dad worked during the week but he came home early as often as he could and would read you and your sister a bedtime story. Your mum worked a couple of mornings a week, and was at home with you the rest of the time. They never had lots of money, but life was comfortable.

• Your dad was diagnosed with cancer 10 years ago and he was told that with the right treatment, he would have a very good chance to be cured. It’s been 8 years since he was given the all clear, and to date, there is still no sign of the disease coming back.

• You have a loving husband and two wonderful children, a rewarding career and things have been good and comfortable for a few years. Things have always been relatively easy for you, but last month you were diagnosed with ca breast. You have had much support from everyone around and your doctor says that with the right treatment, you have a very good chance to be cured.
Case Study 5 years later

• You are now 47. Your cancer recurred a year ago and after months of intense treatment and horrible side effects you have got increasingly worse. You have now been told that your disease has spread widely and that there is no further treatment that can be offered.
The Impact of Working with Death and Dying

The role of professionals supporting relatives/carers
Aims of Session

• Increase understanding of the impact life limiting illness has on carers
• Learn about Prolonged Grief Disorder and to be able to identify risk factors
Impact of illness on carers

• In groups think of and discuss a family you have worked with that had complex psychological and social issues.

• You will be later invited to share this with the wider group so we can think about it together.
Bereavement Support

• Normal grief resolves over time from loss (80% - 90%). (Parkes, 2009)

• Untreated Prolonged Grief Disorder symptoms persist (10%-20%).
## Prolonged Grief Disorder DSM-V

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
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<tbody>
<tr>
<td>A.</td>
<td>Event: Bereavement (loss of a significant other)</td>
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<td>B.</td>
<td>Separation distress: The bereaved person experiences yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree.</td>
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| C.       | Cognitive, emotional, and behavioral symptoms: The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree:  
1. Confusion about one's role in life or diminished sense of self (i.e., feeling that a part of oneself has died)  
2. Difficulty accepting the loss  
3. Avoidance of reminders of the reality of the loss  
4. Inability to trust others since the loss  
5. Bitterness or anger related to the loss  
6. Difficulty moving on with life (e.g., making new friends, pursuing interests)  
7. Numbness (absence of emotion) since the loss  
8. Feeling that life is unfulfilling, empty, or meaningless since the loss  
9. Feeling stunned, dazed or shocked by the loss |
| D.       | Timing: Diagnosis should not be made until at least six months have elapsed since the death. |
| E.       | Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities). |
| F.       | Relation to other mental disorders: The disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder. |

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Risk Factors

- history of childhood separation anxiety
- controlling parents
- parental abuse or death
- a close kinship relationship to the deceased (e.g., parents)
- insecure attachment styles
- marital supportiveness and dependency
- lack of preparation for the death (Parkes, 2009)
- mental health history
- substance misuse
- multiple deaths
Self Care

And supporting other MDT colleagues during loss, grief and bereavement
Aims

• Learn about well being and resilience
• To reflect on your own support system
• Look at how your whole system may be affected by your work
Well being

The state of being comfortable, healthy, or happy

• Easily done when everything is going well
• But what about when things are not going well?
However…

“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”

Resilience

• What do you think resilience is?
• What are the words and attributes that come up for you when you think about resilience?
• If you thought of a resilient tree, what tree would that be?
Strength

The capacity of an object or substance to withstand great force or pressure: *they were taking no chances with the strength of the retaining wall*


The emotional or mental qualities necessary in dealing with difficult or distressing situations: *many people find strength in religion it takes strength of character to admit one needs help*
Resilience

The ability of a substance or object to spring back into shape; elasticity: *nylon is excellent in wearability, abrasion resistance and resilience*

Synonyms *flexibility, pliability, suppleness*, plasticity, *elasticity, springiness, spring, give; durability*, ability to last, strength, *sturdiness, toughness*

The capacity to recover quickly from difficulties; toughness: *the often remarkable resilience of so many British institutions*
Strength Vs. Resilience
How can we support ourselves in adverse circumstances?

Prevention is important and it allows us to protect our vulnerability
10 tips for wellbeing

1. Keep socially active
2. Keep physically active
3. Discover and engage in your hobbies and interests
4. Treat yourself well
5. Share humour

"Just give me the truth, Doc... I can tell when you're trying to humor me."
6. Collect positive emotional moments
7. Learn ways to cope with negative thoughts
8. Do one thing at a time
9. Practise mindfulness
10. Engage your imagination
The Hospice in the Weald

- Breathing spaces (1pm Thurs)
- IPU Breathing space (Tuesdays)
- Yoga class – Monday evenings
- Mindfulness course
- Clinical supervision
- Managerial supervision
- Occupational health
- External counselling
- HitW Community Choir (Tuesday evenings 2/52)
Prevention is not always possible

And so perhaps we can learn to deal with adversity gracefully?
But in losing shape...

Also lies our power to:

• Remain human
• To empathise
• To understand
• And support
Think about your own

- Culture
- Sibling
- Health
- Employment
- Social relationships
- Own family
- Dad
- Mum
- ME