Covid-19

Palliative Care Social Work in response to Covid-19
We believe that all these areas shape the way people think and feel and what matters to them. This includes understanding that people experience pain and distress not only from physical causes but also from other aspects of their lives, such as financial pressures, discrimination and oppression, relationship problems, fears for the future or the loss of a sense of meaning and purpose in their lives.

We work with people in relation to any of these dimensions; in order to support them to live as well as they can, whatever that may mean to them.
Palliative care social workers form a working relationship with an individual person, family, network or community.

They use their understanding of systems to help individuals, families and other groups to negotiate relationship problems and to get the support they need from agencies and services.
A thorough awareness of, and commitment to, the palliative care approach and the principle of living your life the way that you want to for as long as possible

A commitment to people’s self-determination, supporting and enabling them to make decisions in their approach to the end of life and bereavement

A commitment to consider people within their cultural, social and family context, recognising that the definition of ‘family’ varies widely

An understanding of the need to adapt practice and interventions to individual needs and location
Palliative Care Social Work Values (2)

- Confidence and sensitivity in finding the right time to begin to talk about death and dying, being aware that doing this sooner rather than later helps people to be in control, plan ahead and achieve what is important to them.

- A non-judgemental approach that respects people’s different choices, and that celebrates and honours the experiences and cultures that have influenced them.

- Self-awareness and an ability to consider and challenge their own assumptions and bias.
We need to talk about dying...
Infographic from NHS Scotland @ SQS Fellowship
We need to talk about dying...

- What makes it difficult to talk about death in general?

- What makes it challenging to talk about death at the moment, in light of Covid-19?

- What are your worries and fears?

- How do you feel about this now needing to be part of your work (and have you had experience of this previously in your role)?
Talking about dying

- Setting up: Enough time, comfortable place, full attention, open posture
- Opening the conversation: This is something we all need to talk about…
- Invite them to express their own worries and questions
- LISTEN and follow up cues – may need to cut short and talk again later
- Use simple direct language, avoid euphemisms, allow silences
- Give information and be open about what you don’t know, offer to find out if you can
- Summarise what you have talked about and what follow up you have agreed
- Check out how they are feeling now
Questions for people to think about

- If you became very ill how would you like to be cared for?
- What is most important to you?
- Who are the people who matter to you?
- What do you want to say to them?
- Have you made a will?
- Do you have a faith or a religious background? Whether or not you do, would you like to talk to a chaplain or other faith leader?
- Do you have ideas about your funeral? (Bearing in mind COVID-19 restrictions?)
Advance Care Planning

- Advance Care Plans
- Advance Decisions
  - DNACPR
  - Specific treatments
- Lasting Power of Attorney
  - Property
  - Welfare
- Wills
- Preparing messages and leaving memories: e.g. writing letters or cards, making photo albums or memory books, making memory boxes with notes and objects
Reactions to trauma and sudden loss

- Shock and disbelief
- Flashbacks or haunting images
- Anger/ self-blame (often unrealistic)
- Acute fear/anxiety – bodily reactions of racing heart, breathlessness, loss of appetite, insomnia
- Overwhelming realisation that you are vulnerable; preoccupation with sense of impending catastrophe
- Life seems meaningless – lost sense of purpose
‘Normal’ grief responses

‘Grief is the price we pay for love’ (Colin Murray-Parkes)

- Disbelief/momentarily forgetting they are dead, prolonged episodes of crying or sobbing
- Sleep pattern changes: difficulty falling asleep or too little/too much sleep
- An overall lack of energy, feeling lethargic or apathetic about the day’s necessary tasks or life in general
- Changes in appetite: not feeling like eating or eating too much, particularly junk food
- Excessive use of alcohol or drugs
- Withdrawing from normal/usual social interactions and relationships
- Difficulty concentrating or focusing on a task, whether at work, personally, a hobby, etc.
- Questioning spiritual or religious beliefs, job/career choices or life goals
- Feelings of anger, guilt, loneliness, depression, emptiness, sadness, etc. but still occasionally experiencing moments of joy/happiness
- Seeing or hearing the dead person or feeling a strong sense of their presence
Chronic, stuck, or complicated grief

Some of these features are normal reactions in early bereavement but are a source of concern if prolonged

- Maladaptive thoughts: catastrophising; ruminating; pre-occupation with ‘If only...’ thoughts

- Dysfunctional behaviours and body sensations: avoiding objects, people and places that remind about dead person; disrupted eating; over-use of alcohol and or/drugs; spending disproportionate time ‘with’ the dead person – trying to hold onto them by e.g. preserving their rooms and possessions and spending large amounts of time in these ‘shrines’; physical pain with no evident cause; self harm and attempted suicide

- Emotional dysregulation: overwhelming and unstable emotions; insomnia or sleeping a lot of the time; unable or unwilling to experience positive emotions
Loss and grief theories

- Freud: breaking the ties and forming new attachments
- Stage Theory (Kubler Ross): Denial/numbness; anger; bargaining; depression/guilt; acceptance
- Four Tasks of Grieving (Worden): Accepting the reality; processing pain; adjusting to life without them; reconstructing a form of connection
- Dual Process (Stroebe and Stutt): Switching between focusing grieving and thinking about what’s going on in the present
- Continuing bonds (Klass, Silverman and Nicklin)
- Meaning reconstruction (Neimeyer)
- Range of response (Machin)
- Disenfranchised grief
What helps?

- ‘Being with’ people who are anxious or distressed – allowing them to talk and/or tolerating silences
- Listening, normalising and providing reassurance that painful and alarming feelings and bodily sensations are an understandable response to a frightening situation and/or experiences of loss
- Encouragement to maintain healthy patterns of eating, sleeping, exercise, social interaction as far as possible
- Opportunities to express thoughts and emotions through e.g. talking, writing, visual arts, music, bibliotherapy
- Access to chaplaincy, faith leaders, religious observance
- Simple breathing exercises, mindfulness, yoga etc.
- Memorialising through e.g. photo collections, memory books, memory boxes, projects (e.g. fund raising for a relevant cause or charity)
- Taking on a new personal challenge to provide a focus for the future
Caring for yourself and others
Infographic from NHS Scotland @ SQS Fellowship

**Resilience**

"The ability to withstand and rebound from adversity" - F. Walsh

- **Individual Resilience**
- **Relational Resilience**
- **Our Own Strength**
- **Strength from Relationships**

**How to keep on, keeping on...**

- **Be Flexible**: Able to change, reorganise + fit challenges over time
- **Respect Individual (+ your own) Needs, Differences + Boundaries. Pay Attention**
- **Keep Connected**: Mutual Support + Collaboration
- **Keep in Touch with Your Values + What is Important to You**
- **Don't Forget There is a Whole World Out There - and You Are Part of It**
- **Communicate**: Talk to People
- **Rest**: Do Something Completely Different
- **Seek Help If You Need It**
Covid-19 Resources (see also notes pages for previous slides)

Palliative care social work: https://www.apcsw.org.uk/download-resources/


People with learning disabilities: https://www.pcpld.org/links-and-resources/