



PIE AND PALLIATIVE CARE

DR ANNA JEZIOREK-WOZNY
CLINICAL PSYCHOLOGIST
PSYCHOLOGY IN HOSTELS PROJECT (WESTMINSTER)
SLAM NHS FOUNDATION TRUST

WHY TALK ABOUT DYING IN HOMELESSNESS?

- Ultimate destination for all of us – it may evoke fear/anxiety and therefore it's good to increase awareness/comfort to talk about death/dying
- Death is unavoidable – in fact in some way we may be more likely to encounter it in our work due to homeless people's poorer health outcomes than in general population.

E.g. Among homeless people (rough sleeping and emergency accommodation), the mean age at death was 45.9 years for males and 43.4 years for females in 2019; in the general population of England and Wales, the mean age at death was 76.1 years for men and 80.9 years for women (ONS, 2019)

- We all hold own beliefs about dying, death, and loss - e.g. how we die, when we die etc. Good to be aware of these when working in palliative care as they may bring different emotions for us.
- We may have different views about 'saying goodbye' and 'moving on' from bereavement

WHAT IS PALLIATIVE CARE

Palliative care - a holistic approach to care and support for people with advanced terminal illness. It considers the physical, psychological, spiritual, social and cultural needs of the person, and everyone involved in a person's life, such as family, friends and carers. As someone caring for a client this can include your project team (<http://www.homelesspalliativecare.com>).

THE AIMS OF PALLIATIVE CARE

Palliative care aims to address **four** key areas: the physical, psychological, social and spiritual needs of an individual and the people supporting them.

- **Physical needs:** making the person comfortable by making sure any pain and symptoms are well managed.
- **Psychological needs:** making sure that a person has the chance to talk about any worries or concerns they have, and providing emotional comfort.
- **Social needs:** making sure that a person is connected to others that are important to them.
- **Spiritual needs:** making sure that a person is cared for in a way that fits their beliefs (not just religious beliefs).

WHAT PIE CAN LOOK LIKE IN PALLIATIVE CARE

- Palliative care/Grief may begin as soon as we find out someone is going to die
- Develop a collaborative attitude - never impose your ideas and always explore what may be helpful
- Respect the client's "resistance" – see where they may be at in
- Respect the client's privacy
- Ensure you follow-up on their plans and hopes, not just discussions
- Recognise the value of "being" as well as "doing"
- Look after yourself
- Work as a team

CHALLENGES FOR HOMELESS SERVICES

- 'Recovery model' is going to feel different: Recovery -> Quality of life
- Self-neglect
- Setting goals may feel different
- Emotional responses from clients and staff/support network

COMMON EMOTIONAL CHALLENGES IN PALLIATIVE CARE

Helplessness:

- To avoid/manage this uncomfortable feeling we might distance ourselves by coming over-involved or under-involved.
- Under-involved might look like: thinking about other things; wanting to end a session (finding reasons they don't need help).
- Over-involved might look like: staying longer than normal, doing activities outside of your role, trying to do everything, being contacted outside of your work hours

Sadness / Sorrow: Lump in throat, being tearful

- Unable to make a connection with someone because of our own suffering/sadness
- Clients may feel they need to look after us or be responsible for our feelings

COMMON EMOTIONAL CHALLENGES IN PALLIATIVE CARE

Shame/Guilt/Embarrassment:

- Watching the physical and/or psychological decline of someone can be very difficult, losing dignity?
- Looking the other way, avoiding visits, shutting-off conversations; feeling guilty for going home / being OK

Denial and wishing for things to go away:

- Belief that talking about the person's distress will contribute to pain rather than alleviate it
- Trying to 'fix' things, always trying to be positive, not feeling able to sit with the sadness/anxiety

COMMON EMOTIONAL CHALLENGES IN PALLIATIVE CARE

Anger:

- At the disease itself, at our inability to help
- Displacement of anger – blaming others, ‘if only this had been different’
- Splitting between services, angry at someone for not sticking to treatment/support plan?, ‘no point in helping them’

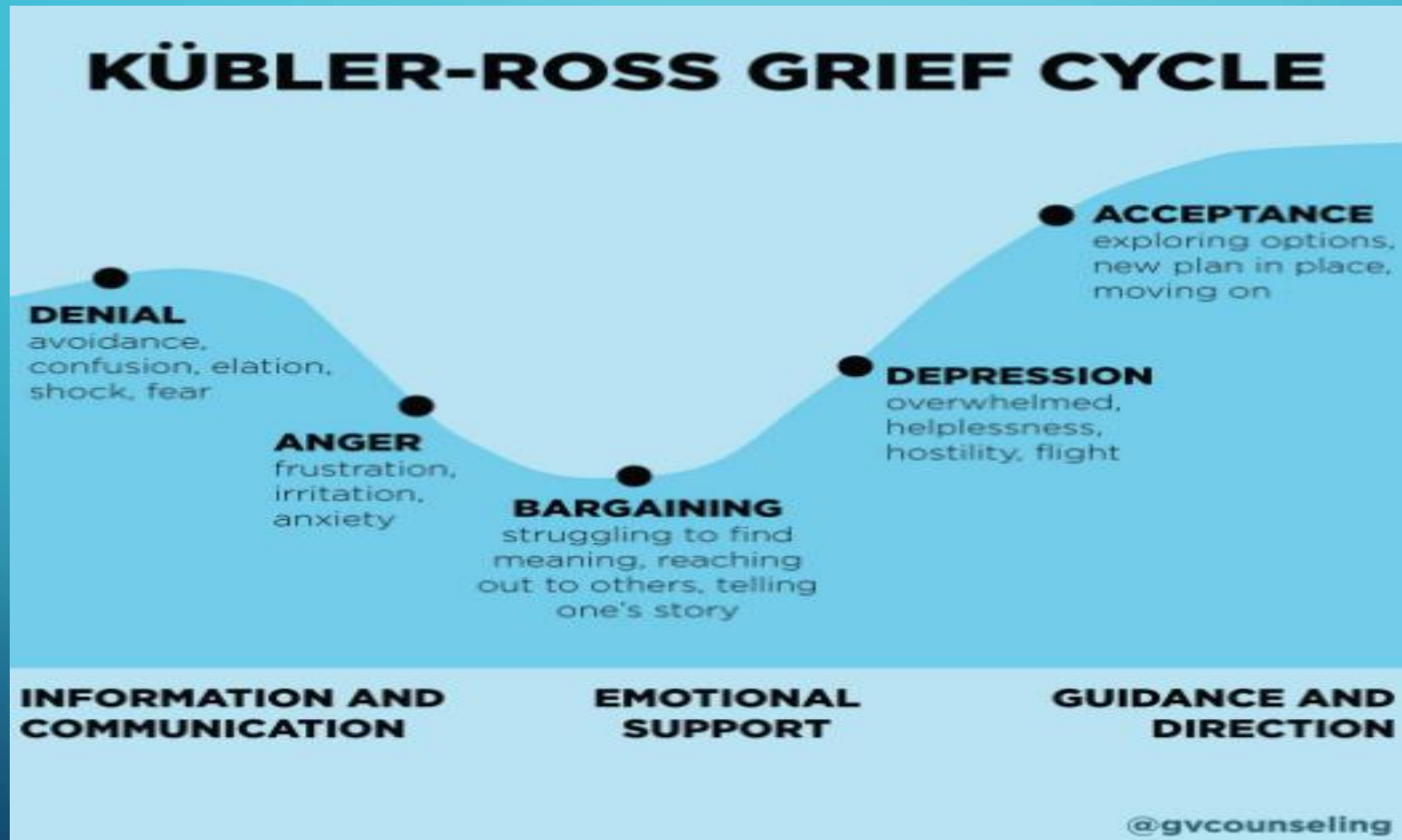
Restlessness:

- Anxious to make things right
- Pushing people to find some value in their experiences
- Trying to speed things up, imposing our own agenda – trying to move someone to do what we think is ‘right’ for them

Guilt:

- Feeling bad about our own health / life / plans
- Not mentioning holidays, avoiding conversations about you / others who are doing well / better
- Enjoying an activity outside of work and thinking about client/feeling bad

SOME RESOURCES/STRATEGIES TO EXPLORE



KUBLER-ROSS CYCLE OF GRIEF

- Rather than thinking of stages, it can be more helpful to think of as experiences which may come and go in random fashion. Some individuals never have each of the experiences listed above.
- In palliative care, it may be useful to think about grief as a visitor that takes on many differing characteristics and emotions as it moves in and out of our awareness.

THE BALL AND JAR METAPHOR

The Ball / Jar Metaphor

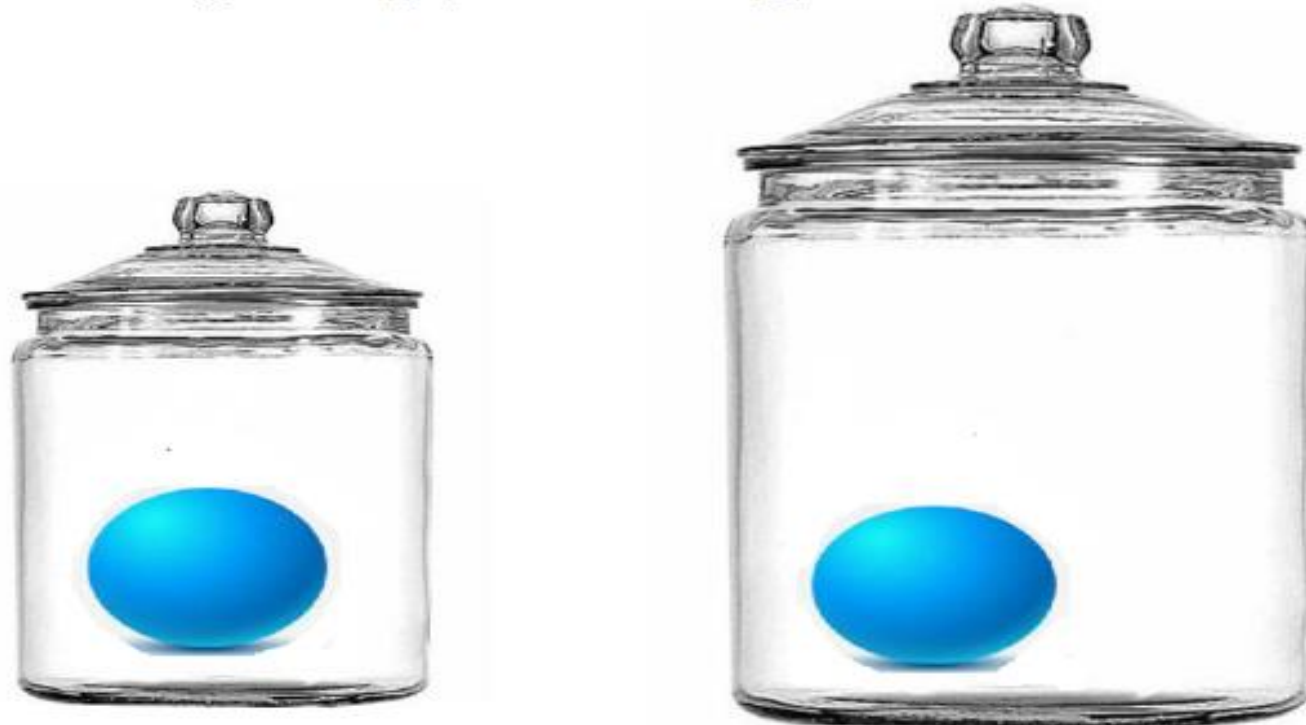
Ball = Cancer / Worry / Distress

Life = Jar

Sometimes when people try and fight the 'black ball' or reduce it, this can be really difficult and may leave some feeling unsuccessful / tired e.g. 'I'm trying to stop myself from being negative – I know it's not good for me'. Sometimes, a different, more helpful way of looking at it can be to acknowledge the black ball and it's size and the roots of why it's there (Cancer is stressful, I do need to be aware of it) and instead of trying to decrease the size of the ball put focus on making the 'life' jar bigger so the space the ball takes up is reduced.

This metaphor has been used with grief, see link for more info:

https://community.macmillan.org.uk/cancer_experiences/bereaved_spouse/f/576/p/108006/875025#875025



HOMELESS PALLIATIVE CARE TOOLKIT

Research informed toolkit with information and resources for staff supporting people who are homeless and who have significant health needs: <http://www.homelesspalliativecare.com/>

Can help with:

- Identifying clients of concern
- Supporting clients' palliative care and end of life care
- Shared care
- Communication about what matters to clients
- Bereavement
- Self-care
- Tools and resources

Lots of useful worksheets that staff can jointly fill out

OTHER RESOURCES

<https://beforeidieproject.com/walls>

- This project puts up ‘before I die, I want to....’ walls all around the world encouraging people to think about what they want to do before they die.
- Can help people reflect about themselves which can then help them feel more comfortable to think about conversations with people they support.
- Free resources on how to set up your own.

<https://www.dyingmatters.org/>

An Initiative where people believe in an open culture that talks about death, and where people feel able to listen and support those who are planning for end of life, who are dying and who have been bereaved.

SELF-CARE IN PALLIATIVE CARE

Develop your ability to be self aware

Reflective practice/Debrief

Supervision

Work as a team – it's not one man's job

Self-compassion

BEREAVEMENT – WHAT TO THINK ABOUT

- How can we support other residents
- How can we support ourselves and each other
- Practicalities
- Planning rituals and celebrations with family, other residents, staff
- Accessing external bereavement services if needed

SOME TOOLS TO HELP THROUGH MOURNING

Photographs and mementoes – can start when the person is alive

Condolence book for staff/residents

Staff debriefs (can be formally arranged with a Psychologist if available)

Memorial services

Things we miss/don't miss – individually and as a team

Goodbye letters

Art: painting and drawing (e.g. hopes and fears about the future)

Thinking time

The background is a solid teal color with a subtle gradient. In the corners, there are decorative white line-art patterns resembling circuit traces or neural network connections, with small circles at the end of the lines.

THANK YOU

Any questions/comments:

AJeziorek-Wozny@slam.nhs.uk