



Cruse Bereavement Care



Exploring similarities and difference when working with anticipatory grief

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Aims for the workshop

- What do we mean by ‘anticipatory grief?’
- Does Anticipatory grief result in a better bereavement outcome?
- What are the similarities and differences between working with people experiencing grief following death and anticipatory grief?
- How can individuals and families be supported and helped?

What do you think we mean by the term:

ANTICIPATORY GRIEF?

How do you consider it to be similar or different to post death grief?

What is anticipatory grief?

- Lindemann (1944) first used term.
- Anticipatory grief as a concept is interpreted in different ways:
 - Relating to grief that occurs in preparation of the impending death
 - A journey towards the ultimate loss through a death, but is composed of adjusting to the many losses, of the past, present and future.

AG: preparing for death

- Anticipatory grief refers to a grief reaction that occurs in anticipation of an impending loss (Casarett, Kutner, Abraham, 2001).
- The term “anticipatory grief” is most often used when discussing the families of dying persons, referring to a normal mourning process that occurs in anticipation of a death (Fulton, et al. 1996)
- How does this conceptualisation of AP reflect your own experiences and knowledge?

AG: adjustment to past, present and future losses

- Evans, 1994: advancing illness provides a cascade of losses for both the ill person and their family members. With open communication about the outcome of disease and a greater awareness of prognosis people in these circumstances may start to anticipate a series of losses that they have yet to experience.
- Rando, (1986) 'grief experienced by the patient, family and others in a life-threatening illness, does not only entail grieving the expectation of a possible or eventual death. It includes grief over all the associated losses – physical, relational, or symbolic'

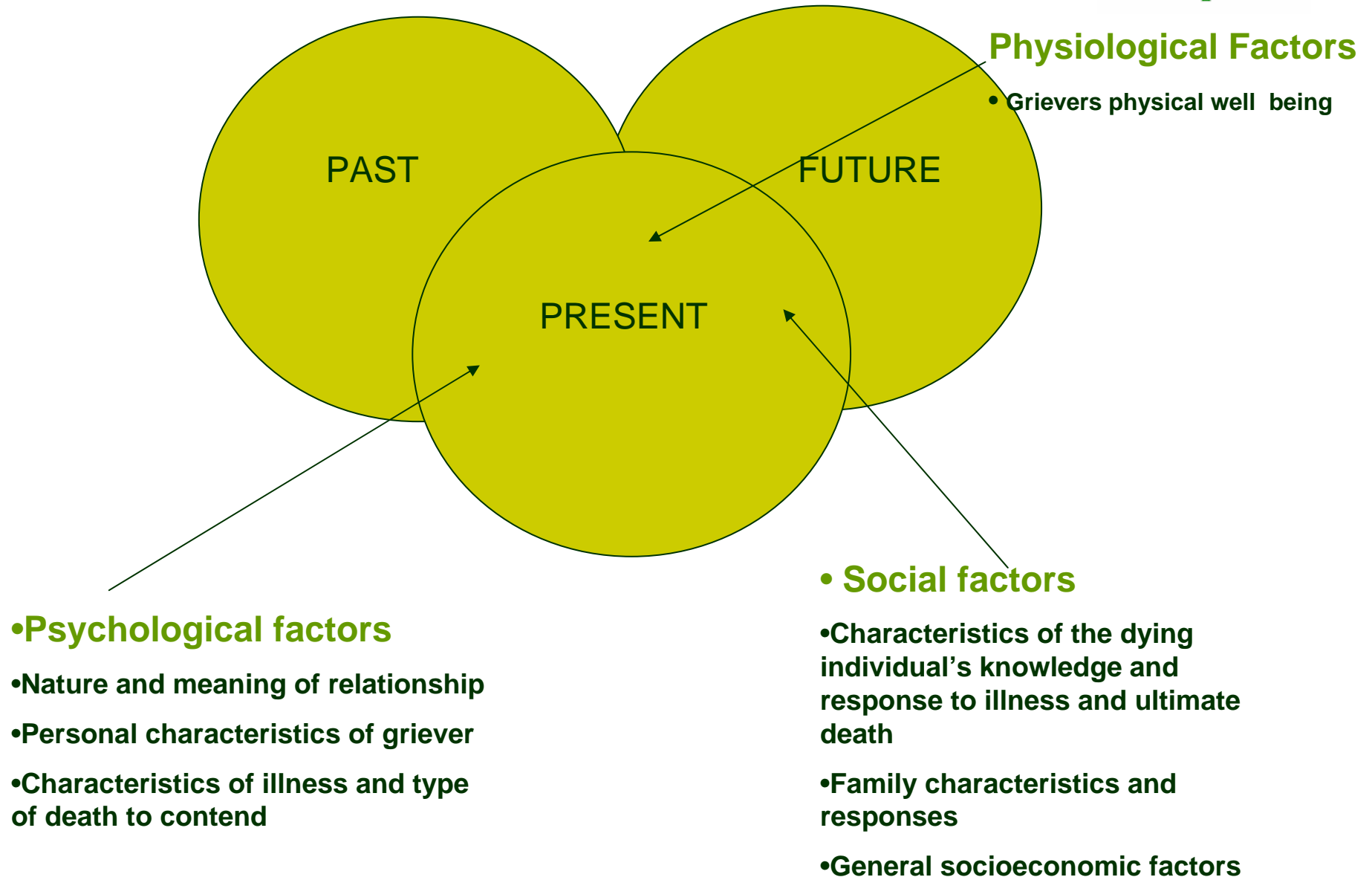
AG: past, present, future

- Rando (1986) three time foci of AG:
- **Past** – the past that was shared and can never be regained
- **Present** – the losses that occur and are experienced as a diminution or outright end of capabilities, ongoing erosion
- **Future** – losses of the anticipated death and such related losses as loneliness and events that will not be shared



Factors influencing AG

(Rando, 1986)





Harry, 20: mum diagnosed breast cancer, 12 years ago. Had a terminal diagnosis for last 4 years.

“Although I know that I have lost her, I feel that I lost her a while ago, perhaps it’s because life changed for me, perhaps it’s because I kind of got used to the idea and I remember lying in bed when they first told us and I would think about what her funeral would be like and I would think about how it would be getting married and having children without her and we kind of talked about those things, I think I cried my tears and got angry then, I can remember when she could no longer drive, I got really angry because it meant that she couldn’t take me to the pub on a Saturday night. I don’t kind of feel that now, just sad and missing her. I think that it helped that she was just peaceful and that she did the things she wanted to do and that helps to.”

Does anticipatory grief result in a better outcome?

- 'I wish we had had time to prepare and say goodbye'
- 'I wish that he'd gone suddenly you know it's been agony over the last two years having all these ups and downs, I thought I was prepared but you know I wasn't nothing could have prepared me, it was still a shock

Research evidence

- Parkes (1975) – paper suggested may be evidence to support people better with warning @13 months
- Hogan (1996) – did not make any difference
- Acorns' work with bereaved siblings (2003) suggests that many of them experience intense anticipatory grief before their brother or sister dies and that it is likely that they will continue to grieve for the rest of their lives.
- Impossible to say because of multi dimensional perspective of grief – too many determinants to simply state this.
- Isn't true that there is a fixed volume of grief and the volume of grief experienced pre bereavement will decrease the remaining grief to be experienced afterwards (Corr et al, 1997)



“I knew for a long time that he was going to die, I never wanted to believe it but deep down I knew, he would often talk to me about afterwards and told me that I had got to be happy. We cried together and laughed together, we were both really angry for a long time ‘why us?’ - I thought that I was prepared, but nothing could prepare me for it. The moment he died, I couldn’t believe that he was gone from me forever, still can’t and I could never have imagined the pain I felt and continue to feel” Debbie, 42



“you know the sun will set every day but every day it is different, I know that every day we are moving a step closer, every day I see the pain and hurt in his face, but every day is different and I am treasuring each one, even though I hate the end of each day because I know it is another day lost, another day closer, and yet it is also another day gained – it is all so bloody difficult and confusing”

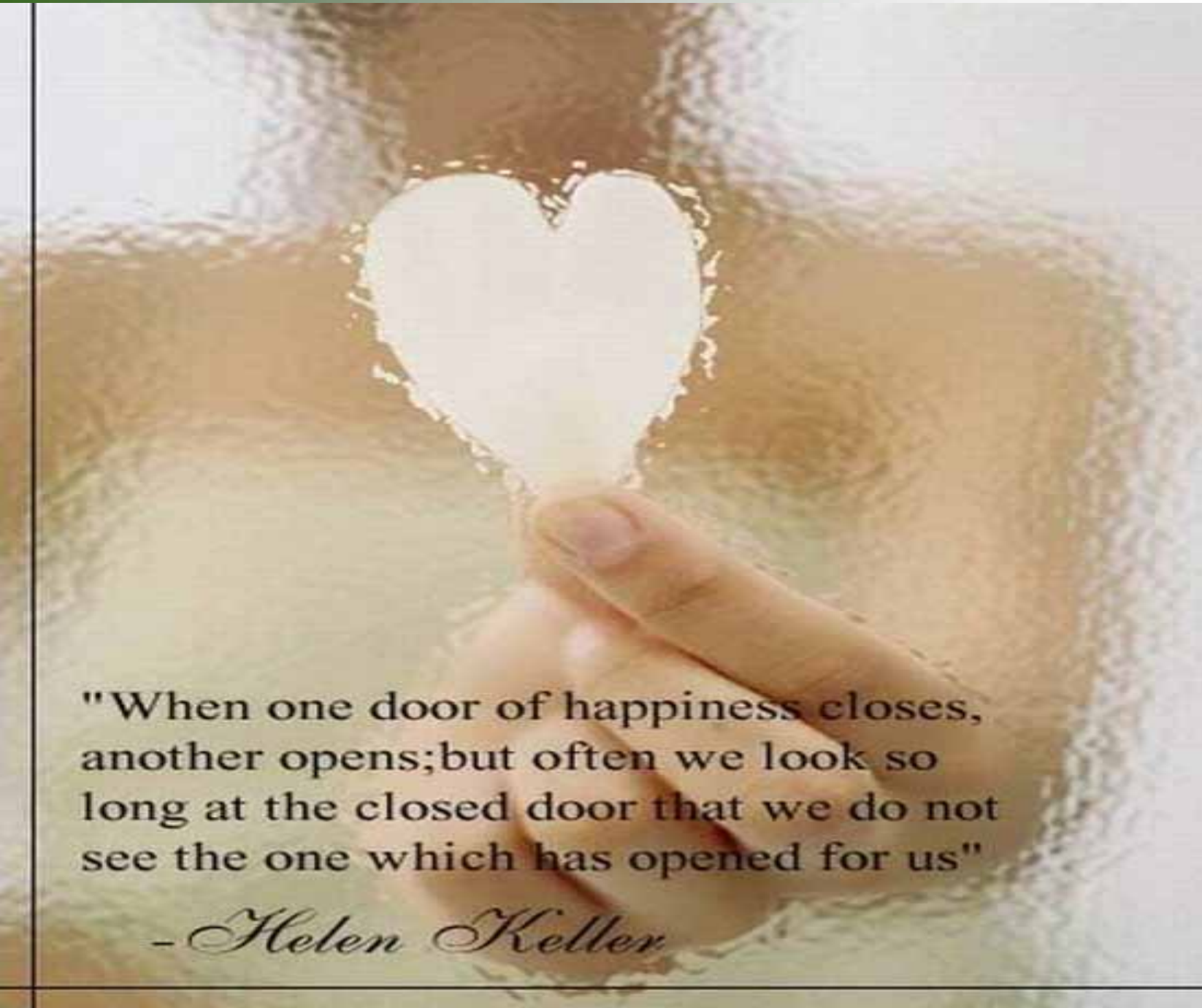


Pre-death grief and sorrow may need as much support as bereavement mourning

Case study

- Debbie is 42. Her dad Gordon is terminally ill with lung cancer. The family are caring for him at home. Debbie describes her relationship with her dad as extremely close, she has asked to come and see you because she feels that she is not coping with life. She says that she finds it incredibly difficult to go and see her dad because he looks so different to a few months ago but that she wants to be a support for him. She says that she is irritable at work with colleagues. One of the main difficulties she has is that he is no longer able to have their regular Friday night teatimes. She says that she knows that he is dying but cannot bare the thought of life without him, she says that she dreamt about his funeral last night and was distraught by this.
- How would you envisage working with Debbie?
- What would your concerns be?



A hand is shown holding a white, heart-shaped paper cutout. The background consists of a close-up of water with soft, golden-brown ripples. The lighting is warm and soft, creating a gentle, reflective effect on the water's surface. The heart cutout is held between the thumb and index finger, positioned centrally in the upper half of the frame.

"When one door of happiness closes,
another opens;but often we look so
long at the closed door that we do not
see the one which has opened for us"

- Helen Keller

Conclusion

- We need to be clear what we mean by AG
- Accept that people may require as much support pre bereavement as post
- Accept AG may be experienced by some but not everyone.
- Accept that knowing someone has a terminal illness provides an opportunity to facilitate discussions which may be helpful in post bereavement outcomes but that this will not be the only factor influencing outcome.
- Know that our skills in helping people post bereavement by being alongside them can also be used pre bereavement as long as we are not using the concept of AG in a prescriptive way, rather as a means of helping us understand what might be going on for each individual.



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