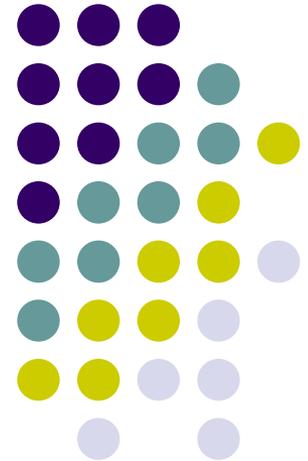
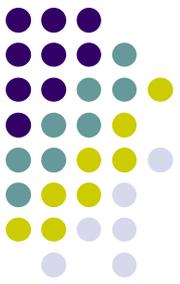


Advanced prostate cancer: being with the struggle

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Understanding cancer related distress



- Threat to self and others
- Connects with loss, death and dying
- Experience often brutal treatment regimes and live with treatment affects, e.g. pain, fatigue, appearance
- Many decisions, many appointments
- Changing physical health context, changing self, changing relationships

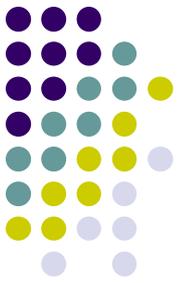
Death talk: Walking alongside distress and being with uncertainty



The threat of death is present

- Connects with experiences of loss, death and dying
- For ourselves personally and professionally
- For the people we help and support
- For our colleagues

Death, dying and mourning



... personally:

- We all experience losses and anticipate future losses and we bring this to our work.
- Many areas of our life influence how we work with death and bereavement generally and at specific times:
 - professional training, personal experiences, culture, religion, age, gender and family.
- Our personal knowledge and experience can constrain or facilitate our ability to have conversations about death and dying.

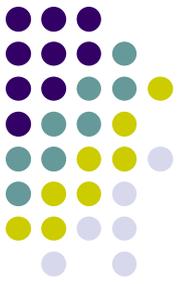
Working with dying, death and mourning affects us...



... professionally:

- Nobody can be an expert in someone else's death.
- Most training focuses on the clinical aspects of our work, whilst the emotional-psychological side can be neglected.
- Feeling unskilled can bring its own stresses and discomfort (see Smith and Martin 2013)

Confusion, helplessness, frustration can arise when...



For professionals

- Tensions are created between professional and personal beliefs/theories/ideas about EOL, and can feel torn between acting in different ways.
- We get married to one idea/theory/policy etc.
- We need to protect ourselves from the pain of entering into the suffering of others (Fredman 2003)

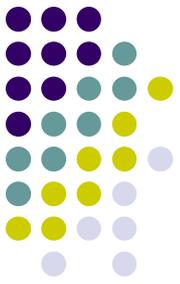
Confusion, helplessness, frustration can arise...



For individuals and families when

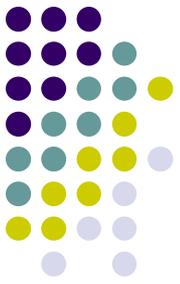
- Conflicts of beliefs in the family, e.g. about the meaning of talking about death, past experience of loss, the NHS, illness. (The stories held are incompatible)
- There is a need to protect self and others
- No sense or meaning can be made, e.g. of pain, dying.
- Limited (internal and external) resources are available, e.g. socially isolated; other physical/mental health problems...

A Challenging experience: helpless, frustrated and confused



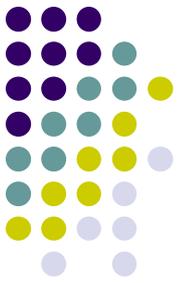
- One person remember a moment when you experienced the above
- The rest of the group listen and remain curious
- What personal values does this connect with?
- What professional values does this connect with?
- What are the main emotions felt and shown?
- How did you behave?

Describing a proud moment: affirming, moved and hopeful



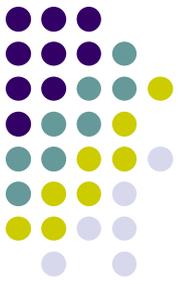
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Some challenges for a supporter



- Managing (feelings about) perhaps not knowing the person, what has happened to them, will I hear from them again?.
- Managing (feelings about) discussions with patients and families about threat of loss and actual loss (physical/psychological changes, change in function, dying)
- Accumulated grief
- Managing (feelings about) uncertainty, 'not knowing' what outcomes might be for a person in treatment
- Working in highly pressured and busy environments that are focused on doing/tasks
- Effects of decision making
- Tension between personal/professional values

What might help our conversations?



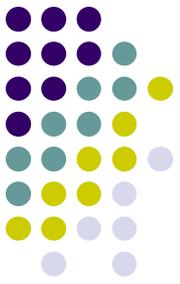
- How does the person make sense of the diagnosis: beliefs, meaning and relationships?
- What is important to the person (values)?
- Foster curiosity and exploration of strong emotion (uncertainty, fear, threat)
- Balance knowing with not-knowing
- When things can't be changed, focus on feelings

Creating a safe environment



- Quiet space, clearly defined, no interruptions (bleep, phone, people coming)
- Be clear on how much time you have and stick to this
- Are there things you need to convey (have to), and time to hear the person
- Do not make promises you know you cannot keep
- Agreed way of following up-date/time what fits for the person? (team protocol)

Help make sense together



- More to experience than a medical or psychological story can tell
- Create something with the person/family
- Create a context and place of safety
- Be with rather than avoid that which cannot be changed



Remind ourselves that...

- There is more than one way to live with a life limiting condition
- Certain ideas about how someone *should* be doing this gain currency/privilege
- To balance knowing and not-knowing (curiosity/hearing/being alongside a person)



Thank you