

Session 26

Caring & communicating in chronic & Life threatening disease: arthritis, heart disease & cancer

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Breaking bad news

Adapted from the Bayer Institute/ CPCRE communication in palliative care resource.

An approach to use - HEAR

- Preparation
- Hear
- Explain
- Acknowledge
- Repeat
- Closing

Prepare – privacy, self-reflection

- Check if he wants a family member or friend present
- Don't presume that he has an understanding of the situation – check what he knows/believes (and remember this is shaped by past experience, including “irrational” thoughts)

Explain

- Find out what the patient wants to know
- Level of information
- Type of information
- Match language with patients
- Check for understanding – *“I would like to check that I have given you all of the information you need, so can you run over it for me so I can be sure?”*
- NOT *“Do you understand?”*

Acknowledge: Show Empathy

- What is empathy?
- Person experiences being seen, heard, and understood
- It is not sympathy
- Shown by
- Reflective listening
- Acknowledgment and validation
- Educated guesses, especially with a psychosocial focus: *“I can imagine this is very hard to here for someone as independent as you”*

Repeat as needed

- You may need to cover the same ground a number of times
- After the first shock, the memory closes down
- Repeat answers to questions, not all the information
- Be prepared to think about and respond to the “hidden” communication/emotional issue in questions: *“I'm going to get better aren't I?”* is a communication of fear and uncertainty, and an appropriate response is: *“This is pretty scary”* before a detailed presentation of prognostic information
- Check understanding

Closing

- Instill Hope
- Offering the most up-to-date treatment available
- Emphasizing that new treatments are always emerging
- Willingness to seek further information or a second opinion (Sardell & Trierweiler Cancer 1993;72:3355-65)
- Indicating that the patient's needs and concerns are of central importance in their care
- Stating that although the information gives an overall impression this is an average, and there are always some people who do much better than average
- Time
- Take time, don't rush
- Follow up

Validating the journey

- Communication
- Knowledge and understanding
- Illness as a journey
- Information
- Pacing
- Acceptance
- Hope

Decision-making at critical time-points For the doctor:

- Deciding what is "right"
- Conflict of interest
- Stakeholders
- Timing
- During discussions
- Unbiased presentation
- Amount of information – language, framing etc

Transition from curative to palliative

- Changes everything
- May survive many years
- Open and honest communication
- Not abandoning them
- Always choices
- Scrupulous attention to symptoms and their needs
- Respect for their decisions

Living until you die

- Demoralisation:
- Feelings of helplessness, hopelessness and meaninglessness
- Challenge to sense of self and personal integrity
- Loss of dignity:
- Feeling degraded, ashamed or embarrassed
- Changes in appearance and bodily function
- Sense of being a burden to others
- More likely in younger patients

Responding

- Acknowledge the uncertainty – the marathon
- Respect the humanity and identify “personhood”
- Re-frame accepting help whilst acknowledging the grief – allowing others to help is a gift you give them
- Explore the sense of control and autonomy – accepting some help allows you to choose to use your energy on things that matter
- Helping the person see things from a different perspective (not the same as “looking on the bright side!”)
- Denial is not a bad thing unless it gets in the way of family issues and treatment
- Bearing the pain