



PATIENT SAFETY TOOL BOX TALKS®

EFFECTIVE CARE & SUPPORT

END OF LIFE CARE: ANSWERING DIFFICULT QUESTIONS

v1.0



"Am I dying? ", "I am not getting better, am I?", "Can I go home?", "How long have it got?" ...

When a patient is concerned about something, he/she will carefully chose who to ask or speak to, and this choice will be based on the patient having some sense of who they thought might be the best person for whatever reason.

If the patient is asking you, it is because they believe you will help. Your job is to hold that trust and explore their concerns.

"Research has found that end of life care decisions made too close to death cause unnecessary stress for both patient and families" (C. Grbich et al, 2006)

Lack of discussion can lead to decisions made in crisis, e.g. unnecessary hospital admissions, lack of necessary support being available, family wanting 'everything' done because they haven't had time to process.

A simple response might be:

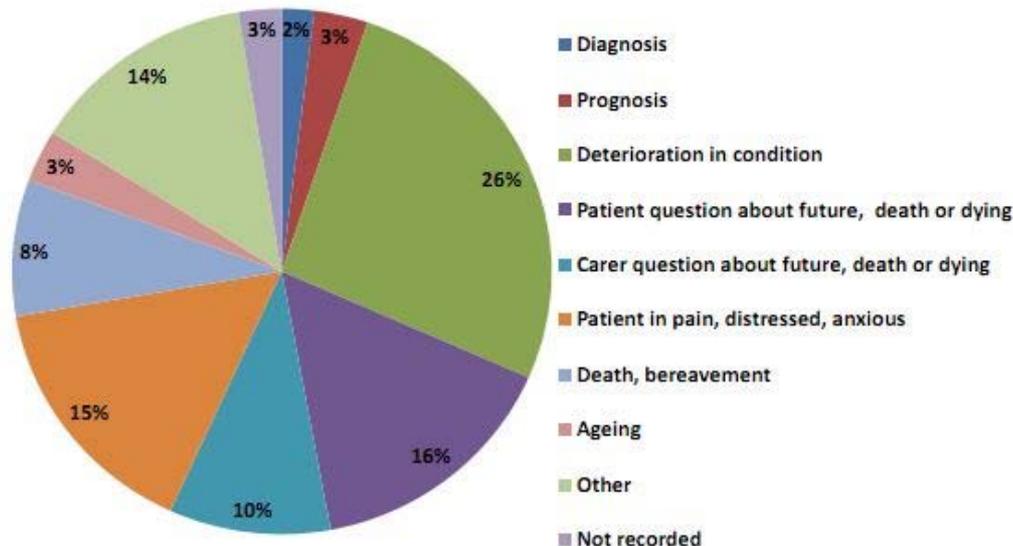
"Do you feel that bad today?", "Are you worried about something?", "Are you worried about anything in particular?", "How can I help?"

Being around people at end of life or people who are upset challenges all of us on many levels. There is a focus on keeping patients happy and comfortable. This is not always possible and patients will flag their concerns, sometimes when it is least expected. For example, you may be doing a person's dressings, giving out medication "these tablets are not really working anymore are they?" While helping a person to wash "I think I am finished", "I think I am dying". Such statements are often met with "Not on our shift", "You're grand" or "don't worry" but they really demand more attention from you as a healthcare provider.

It is normal to feel uncomfortable when difficult questions are asked but it's important not to panic and to find out what lies behind the question.

Conversation triggers

The triggers for 155 conversations with patients, family members and carers when GPs discussed end of life



CAN WE TALK HERE?

There may be an issue for non-clinical staff about how much they might be 'allowed' to say (how much clinical information they're allowed to provide), but the key is that conversations are allowed to happen, that the person is allowed to ask for information, and is not shut down. Keep the communication open.

Difficult Questions



Evidence shows that when a person is approaching the end of their lives, he/she can be excluded from all meaningful discussion about what matters to them.

In my role, can I make sure this does not happen to those in my care?

Always remember

1. Deal with concerns before details
2. What is this person most worried about at the moment?
3. I may not have the answer but I can listen and link the person with someone who can

The difficulty in responding to difficult questions can often be my own anxiety about having the right answer for the person and wanting to make it better. It is not about having the right answer, rather allowing the person to express what it is he/she is worried about and accessing support.

National Audit on End of Life revealed that staff are more comfortable discussing the person's needs with the family rather than with the person.



Remember !!!!:

- Don't panic!
- Don't avoid the question
- Don't rush a response based on your own discomfort
- Keep communication open
- Gently probe to find out what's behind the question: **"What makes you ask that?"** or **"How are you feeling?"** or **"What is your biggest worry at the moment?"**, **"Are you feeling worried/afraid?"** or **"What do you understand by what the doctor said?"** or, simply **"How can I help?"**
- It's also okay to say **"I don't know"** if you don't. It might be appropriate to say you cannot answer the question but you will try to find someone that can help

Be an Active listener:

- Be aware of your body language
- Maintain good eye contact
- If possible sit down with the person.



Key points in listening well

- Don't interrupt
- Do paraphrase, "What I hear you say is"
- Do clarify, but keep questions until there is a natural pause
- Do give your full attention
- Do not pretend to understand if you do not
- Don't think of your own input "What will I say next" instead of listening to what the person is saying
- Acknowledge the person's concerns



What Makes Up What We Hear

