Prompts for discussing End of Life Care Issues

It is acknowledged that there are several reasons why many individuals have difficulty in communicating with dying persons: not wanting to face the reality of our own death, not having the time to become involved, and not feeling emotionally able or confident to handle such intense situations. However, for many people, discussing the dying process, where and how they would like to be cared for, and thinking about how their last days, weeks and months might be spent, can be very beneficial. It is therefore important that the barriers that families, doctors, nurses and care staff experience can be overcome if the process of dying isn't to become a forbidden topic.

Some of the ways that carers (professional or otherwise) demonstrate their unease with dying people are:

- Avoiding the dying person
- Having difficulty speaking or maintaining eye contact with the dying person
- Keeping their distance
- Not wanting to touch the dying person
- Unwillingness to listen and pick up cues

This may result in over-concern, hyperactivity, or manipulative and impersonal behaviour e.g. 'aren't we looking good today', or simply by changing the subject. Carer's unease is likely to be perceived by the dying person as frustration or rejection because no-one will listen to them and therefore their needs aren't being met.

Important steps in communicating with dying people and their families

For people who are dying (and their families), the prospect of their own or a loved one's death can be a frightening experience. Being able to talk about the quality or length of time left, the disease process and feelings about family members or friends is very important. Communication (both verbal and non-verbal) is a two-way process where each person is trying to give and search for cues about the other person, and whether they are open to such an in-depth conversation.

<u>Skills needed to communicate effectively</u>

Some of the following may help to facilitate open communication with residents/relatives.

Listening – an active skill which requires great concentration if a person's cues are to be picked up.

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Silences – allow people time to think and assimilate what has been said. Have the confidence to just sit with someone, hold their hand etc. Words aren't always necessary to help convey feelings and that you are there for someone.

Acknowledgement – indicates that you have heard the person – just a simple nod of the head, a 'yes' or 'mmm' is enough to let them know you're paying attention and are interested.

Encouragement – this is more active than acknowledgement. By showing interest the person is encouraged to continue – 'really, that's interesting, do go on' or 'I'm trying to understand how you feel' or 'what do you need to do/would like happen now'?

Picking up on cues – residents/relatives may drop hints or cues about problems. The skill is in listening and picking up on those cues – 'do you think I'm less well'? – can be turned round and carers can ask back 'why, are you feeling less well'? The person will often answer their own question by explaining why they think they're less well. OR – 'I didn't like going into hospital again last week' could be answered with 'don't you want to go into hospital again'? or 'what didn't you like about it'?

Reflection – encourages people to talk about a topic or problem they have raised and may want to discuss. Send the topic back to them: 'you say you've been feeling low, in what way?'

Open questioning – ask questions that allow people to express themselves – 'how do you feel today?'

Empathy – show that you understand the persons point of view which will encourage them to talk in more depth – 'it sounds as if it has all been very difficult for you lately'.

Behaviour that blocks open communication

When communicating with residents/relatives, care staff need to be aware of the following traps!

Information giving - nurses/carers who feel anxious may try to give information as a way of deflecting the conversation away from an emotional area. Stick to what the person needs. For example: 'I'm feeling fed up!' Instead of asking the person if there is anything in particular they are fed up about a nurse/carer could say that they will contact the GP who has a counsellor that they could be seen by..... Pick up on the obvious before offering other alternatives/information.

Normalising or belittling – the following example shifts the focus away from the individual and how they're feeling: 'everyone feels anxious when they think of dying, it's normal.' This sort of comment makes the person feel stupid and they are unlikely to pursue this further, even if they have a specific issue they are worried about. A better response would be: 'Most people are anxious about dying but is there anything in particular that you are worried about.' This response reassures the person that they are not alone in their fears but allows the person to be more specific if they want to be.

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Premature or false reassurances – don't fall into the trap of trying to make things sound better than they are: 'don't worry about what the doctor is going to say, it was fine last time and I'm sure it will be this time.' Acknowledge their fears and if you are feeling brave ask them what they think might be wrong! This can help the person who tells them bad news if they are going to be confirming good/bad news and help them to approach the person more sensitively.

Leading questions – a question asked in a way that influences or predetermines the response will not help open communication: 'you're looking very well, you must be feeling better.' A better approach might be: 'How are you feeling today?' You can then go on to compliment them if this is appropriate.

Closed questions – don't ask questions that restrict the range of responses to 'yes' or 'no'. The only exception to this is when a person hasn't the energy to speak much. Then questions can be phrased simply to gain a yes or no response to direct the conversation.

Multiple questions – don't ask one question on top of another, and don't answer your own questions: 'how are you feeling? Are you less tired? You seem much more rested.' People can rarely remember everything that's been asked.

Passing the buck – don't suggest they ask someone else their question. If you can't answer them tell them you will find out. People usually ask who they're most comfortable with. If you don't follow it up the person might not ask someone else.

Defending – when residents/relatives are angry and worried, don't make excuses for the situation: 'the doctor is very good – he's the expert.' Allow them to express their feelings and then pick up the pieces once they've calmed down and are more rational.

Changing the topic – don't ignore a cue or a question from someone by introducing a new or unrelated topic. They may not make a further attempt to make this feeling known. For example: 'Am I dying nurse'? Don't answer with a response such as - 'Of course not, you look much better today'. Instead, take a deep breath and ask them why they think they might be dying.

Selective attention to cues – don't just address the physical needs but pay attention to emotional aspects too. A person struggling with thoughts and feelings can experience equal amounts of discomfort compared to a physical pain. Asking a person how they feel about something, or how it has affected them, helps to address the emotional, psychological, social and existential aspects of life.

Jollying along – trying to make the person look on the bright side can make them uneasy about stating how they really feel. This needs to be balanced with encouraging someone to do a task, e.g. getting out of bed.

Personal chit chat – chit chat moves the focus of interaction away from the person and their concerns. Sometimes a person is glad of the distraction but make sure cues are picked up on when this is no longer wanted.

Summary

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Building up good communication and listening skills, touching and maintaining eye contact, and projecting a genuine sense of empathy all give the message that we are there to help and support the person/family, and that we care about how they are feeling. In short, effective, empathic and timely communication is necessary to facilitate to good advanced care planning and end of life care.

It is important that the residents feelings are heard and addressed first, followed by the relatives. If this is not appropriate or possible e.g. where a resident lacks capacity, or the relative is requesting actions and treatment that may not be in the best interest for the resident, use one or more of the techniques above to find out in greater depth why they are requesting such actions. They may not understand the full implications of their demands or feel so distressed they may not be aware that their requests are inappropriate.

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