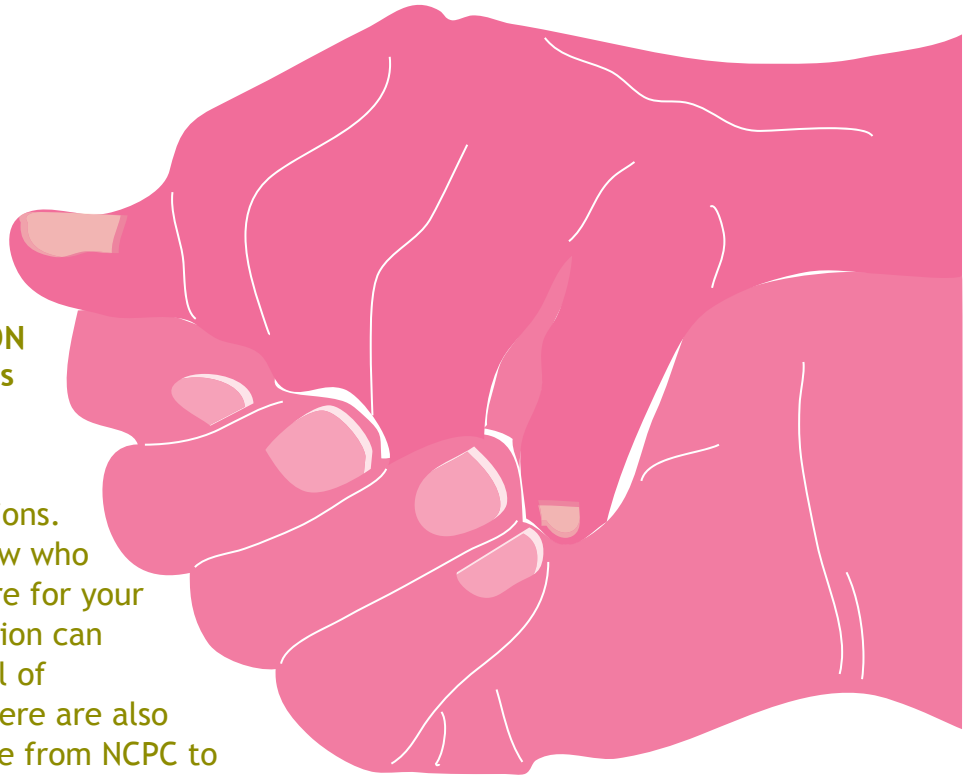


## HAVING THE CONVERSATION

### End of life care discussions

The first step of this care pathway is communication and end of life care discussions. It is important that you know who the end of life care leads are for your area, so that your organisation can access the appropriate level of communication training. There are also learning workshops available from NCPC to help with this aspect.



## THE END OF LIFE CARE PATHWAY

STEP  
1

Discussions as end of life approaches

STEP  
2

Assessment, care planning and review

STEP  
3

Co-ordination of care

STEP  
4

Delivery of high quality services

STEP  
5

Care in the last days of life

STEP  
6

Care after death

Keeping the channels of communication open in relation to residents who are nearing the end of their lives is a fundamental part of good end of life care. There is no mystery surrounding ways of communicating with people nearing the end of their lives and their respective families. However, it is a skill which requires staff to be honest, empathetic, with an ability to take into account others' feelings including those that are openly exhibited and those that may be hidden.

However to do this you need to have explored your own feelings around death and dying so it is important you complete Module 1 first. If you do this and develop the skills to communicate effectively you are likely to get a great deal of satisfaction knowing that you've cared for someone through their life and death.

Good communication is based upon sensitive listening, having good observation skills, and the ability to assess the information needs of the resident and their family/care. It is essential to listen to what they and their family are telling you and to pick up on their non-verbal cues. This becomes even more important when the person you are caring for has cognitive

SAMPLE

impairment, such as dementia. Research and experience demonstrate that it is possible and worthwhile to communicate with people in the later stages of dementia. Communication may be in forms that are non-verbal and/or difficult to interpret. The time and skill to interpret cues is therefore vital. With regard to accuracy it is crucial to understand that to the person with dementia, what they are saying or communicating is true and is an expression of their feelings or experience. It will be a challenge but it is essential to focus on the meaning behind the words. When someone has dementia it also makes it even more important to listen to what their family/carers say as they may well understand and be able to interpret cues (see further reading section). It also needs to be recognised that nursing or care jargon may not be understood by the resident or family/carers leading to genuine misunderstandings.

### Recognising when end of life care discussions should occur

Staff regularly tell us that they find it hard to recognize when people enter the end of life phase and this is why they don't have these conversations or help the person to plan. Given this, it is important to recognise that residents and family/carers tell us they would rather discuss end of life care, acknowledging that its difficult to be certain about timings,

than not discuss this at all. One of the biggest complaints in healthcare is that family/carers recognise someone is dying but staff don't communicate this.

This highlights the importance of recognising the unpredictability but alongside this starting these conversations early so that people have time to plan. There are some tools that can help with this, for example, ask yourself:

**“Would I be surprised if this person died within the next year?”**

### Starting the conversation

If the answer to the question above is “No” then you should start opening the conversation with prompting questions such as:

- Can you tell me how you are feeling?
- Is there anything you would like to discuss about the future?

These are very open questions and you may be surprised how willing people are to talk once the conversation is initiated. You should always give the resident the choice of whether they have the conversation in private just with yourself or with family/carer present. Often, once staff have built up the confidence to start the conversation they are surprised to find that the resident has been desperate for this conversation to happen for some time. However there may be points at which the resident's feelings, wishes and needs may require more probing. Some questions can help with this, such as:

- What happened next?
- What else was happening?

If it does not feel right to use probing questions a good way to help people open up is to reflect back to them what they have said and then explore this further, such as:

So you mentioned the shock at hearing the news, what happened next?  
 So you felt upset by the symptoms, what was describing?

