

Leaflet # 6: Remember when we...

Starting the conversation if someone close to you is dying

Someone you know is very ill

They may not have long to live. You feel desperately sad, but also at a loss what to do. Their illness seems to have changed everything. How can you talk about things the way you used to? Will they still want to see you when time is so short? Should you call? And what can you possibly say to them under the circumstances?

"It was very hard to talk about the end of his life because my husband was a very proud man. But we sat down, and faced the fact that this was it. It was tough, but it was also very emotionally helpful. And in the end, there weren't any surprises – he died as he wanted to."

Why we need to talk about death and dying

Some people don't die as they might have wished to. They may not have left a will, or expressed wishes about their funeral, care arrangements for dependents, or donating organs. Or they may simply not have said what they wanted to say.

This isn't just sad for the person dying. For those left, there may be difficult loose ends to tie up, and sadness and regrets that can live on for a long time. It's in everyone's interests to deal with these subjects, and to talk about the practicalities and emotions surrounding dying, whether it be years or days away.

The process isn't easy. It involves facing an uncertain future, accepting that things are coming to an end, and acknowledging strong emotions like love and fear.

But it can bring you closer, and families commonly report a sense of relief once dying is brought out into the open.

Subjects you might need to talk about

- The type of care someone would like towards the end of their life
- Where they'd like to die
- Funeral arrangements
- Care of dependents
- Organ donation
- How they'd like to be remembered
- Whether they have any particular worries they'd like to discuss about being ill and dying
- What they'd like people to know before they die

Principles to bear in mind

- It's generally true that, in the long run, you hurt people more by the conversations you don't have than by the conversations you do have.
- It's quite likely that the other person has been thinking about these subjects for a long time – they just haven't shown it.
- Sometimes talking about important subjects like this isn't a matter of having one "cover all" conversation – it can be many small ones.
- If you're worried about getting it wrong with someone you love, you can always discuss what to do with someone else you respect and trust – a nurse or close friend, for example.

Starting the conversation

- Choose the right place, and the right time. No one finds it easy to talk if they're feeling particularly stressed.
- If there's time, it's best to wait until there is an obvious indication from the other person that they want to talk.
- But when time is short, you may need to raise the subject directly. You needn't be harsh or abrupt. You can be honest and acknowledge the difficulty: "I know talking about these things is never easy."
- One good way to provide an opening is to ask the person how they feel about their illness, or their progress, and what they hope for in the next few weeks.
- Try and be honest and personal from the start. It can help if you make it clear why talking about this subject is important to you.
- If the other person clearly doesn't want to talk, or openly face the fact that they are going to die, you do have to respect that.
- Listen to the other person, and show you are listening, for example by nodding your head.
- It's good to be reassuring, but you can overdo it. For example, if you say "Don't worry", it might stop the other person from talking and being open about anxieties.

During the conversation

- Let people feel free to express any anxieties they have, and don't worry if you or the other person gets emotional.
- Avoid making the other person follow your agenda for the conversation – it's more a matter of providing obvious opportunities for them to open up.
- If you ask questions, try keeping them open: "Is there anything you want us to know...?" rather than "What have you done about a will?" You may find subjects arise without asking directly.
- If general questions don't work, and time is short, you may need to be more specific.
- Be honest about your feelings.

Do...

...remember that we are all dying. Conversations about dying can be two way, with both participants talking about plans, memories, fears and hopes for their own death and after.

Don't...

...fill silences: gaps in conversations can provide people with the opportunity to bring up subjects that are important to them.

Try...

"How do you feel about your situation at the moment?"

"What would you like to talk about?"

"I know these are difficult things to talk about..."

"Is there anything you want us to know...?"

"How do you feel you're progressing?"

"What do you hope for in the next few weeks?"

To find out how to get more help visit www.dyingmatters.org

or call freephone 08000 21 44 66

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



This is number six in a series of leaflets focusing on dying, death and bereavement produced by Dying Matters.

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland.

Registered Charity no.1005671