



Leaflet # 5: To do list

Information for ill and older people who want to start conversations about the future with family, friends or carers

There are things you want to raise, but it never feels like the right time

Many of us don't want to ignore the fact that our time is limited. There are things we want to get sorted out – like instructions for what we'd like to happen at and after our death.

We may want to talk to those close to us about our feelings for them, or what should be done if we become dependent, or what happens to those who are left behind. But these aren't easy subjects to raise.

"I've tried to bring up the subject with my children, but they really don't want to talk about it because I think they're frightened themselves."

Why we need to talk about death and dying

Talking about death doesn't bring death closer. It's about planning for life, helping you make the most of the time that you have.

But often family members find it hard. Here's what one woman said: "My kids aren't up to discussing the fact that I might not live very long. I've left instructions with the hospital about my wishes, but I'm praying that in the rush everything doesn't get forgotten. I want to make my children realise that I want to talk about these things. It's not a matter of sitting down and crying, but of sorting things out."

Starting the conversation, particularly with those close to you, is never easy. We don't want to upset people, or sound gloomy. But families commonly report that it comes as a relief once the subject is brought out into the open, and everyone faces the reality of the situation.

Principles to Remember

- If there are issues that you want to talk about, you are perfectly entitled to raise them.
- We all worry about hurting people by talking openly. But it's generally true that in the long run you hurt people more by the conversations you don't have rather than the conversations you do have.
- Sometimes it's actually harder to talk to those close to you than those with a little objectivity. You may want to talk to someone else first – a trusted friend, a nurse, GP or doctor at your hospital or hospice, or even a professional counsellor.

Subjects you might want to talk about

In the checklist below are some of the areas that people often leave it too late to discuss.

- The type of care you would like towards the end of your life
- Where you'd like to die

- How long you want doctors to keep treating you
- Funeral arrangements
- Care of dependents – children or parents
- Organ donation
- How you'd like to be remembered
- Worries you have about being ill and dying
- What you'd like people to know before you die
- How you feel about people

Starting a conversation

- Choose the right place, and the right time. No one finds it easy to talk when they're rushed or in a stressful situation.
- You may find it easier to wait until there is an obvious prompt - the recent death of someone you know, or a newspaper article, for example. You can then turn the subject around to yourself: "I wouldn't like that to happen to me."
- It's often better to raise the subject directly. If you make it absolutely clear that it's a subject you want to address, things can start to fall into place. The people you are talking to then feel they have permission to talk openly too.
- It can sometimes reduce resistance to the conversation if you ease into it with an acknowledgement that it's difficult: "I know talking about these things is never easy".
- Be as honest and personal as possible from the start. It can help if you make it clear why talking about this subject is important to you. "I've been worried about some things and I'd like to talk about them."
- If it doesn't work first time try again a day or two later.

During the conversation

- Try to make sure you say what you want to say: it's all too easy to back away, or play down your concerns, if you're worried about causing a fuss.
- Don't worry about the conversation turning emotional. People often stick to the practicalities so that they avoid upsetting areas, but doing this can mean that the things that matter most don't get aired.
- You may want to reassure the other person that just because you've raised the subject of your death, it doesn't mean you're going to die tomorrow.
- Listen to the other person. If you show that you are listening to them, it's more likely they will listen to you.

Why not try...

...writing a letter, explaining how you feel, and setting down the things you'd like to talk about

...giving a present that has some emotional significance to you or the person you are giving it to, with a note explaining it, your feelings and wishes

...giving someone a list of the things you've loved about your life, and the things you still want to do, along with a list of the things you want to get sorted out.

"It's not so much dying that I'm worried about, but making sure that everything is sorted out for the people who will be left behind."

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

or call freephone 08000 21 44 66

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This is number five 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.

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