

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.

Practical help

There are a range of organisations that can help you plan the support and care you need towards the end of life, advise on writing wills and living wills, and provide advice on the emotional issues surrounding dying. They can be found at www.goodlifedeathgrief.org.uk

"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."

There are things you want to raise, but it never seems the right time.

Many of us who are getting on in years, or have an illness that we know will shorten our life, 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 – especially when those around us seem to want to ignore them.

To find out how to get more help visit:
www.goodlifedeathgrief.org.uk
or call 0131 229 0538



Good Life, Good Death, Good Grief is working to make Scotland a place where there is more openness about death, dying and bereavement so that:

- People are aware of ways to live with death, dying and bereavement
- People feel better equipped to support each other through the difficult times that can come with death, dying and bereavement

We are interested to hear from any person or organisation who wants to work with us to make Scotland a place where people can be open about death, dying and bereavement.

This leaflet was originally produced by the Dying Matters Coalition which aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement. Dying Matters is led by the National Council for Palliative Care, the umbrella charity for palliative, end of life and hospice care in England, Wales & Northern Ireland: www.dyingmatters.org
Registered Charity no.1005671

TO DO LIST

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



Dying Matters

Let's talk about it

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.

Some people have the sort of relationships where this is understood – where families and loved ones can express love and fear, be open about the future, and acknowledge that life is finite. But many of us don't, no matter how much we love each other. It's hard to face an uncertain future.

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 on what treatments I want and don't want towards the end of my life, 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, and my will, and what happens to my own parents when I die. It's not a matter of sitting down and crying, but of sorting things out."

This leaflet aims to provide some pointers on how – if you want to – you can try and start these conversations about dying. You should feel you have a right to do so. Even if there are no easy answers, discussing them can help you and your loved ones gain more peace of mind, and get on with living life.

"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."

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. Some may be more important to you than others. If you want to know more about any of these areas, then go to the Good Life, Good Death, Good Grief website at www.goodlifedeathgrief.org.uk

- 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, for example
- 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

"I think you've just got to come straight out with it. I did it by making a joke about them being after my money, and then it slowly opened up from there."

What to do if you want to start a conversation

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.

There is no right way and wrong way to talk about dying. It's up to you and those close to you. But the longer you leave it, the more difficult it can become.

Here are some ideas that may help:

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.

Starting the 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." The problem with this approach is that you can wait for ever for the right opening.

- 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, with less fear of upsetting you. Beginning the conversation comes as a relief to everyone.
- 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"; or maybe a question: "Do you think we ought to talk about...?"
- 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. It's harder for others to avoid the subject if it's obvious that it affects you deeply. "I've been worried about some things and I'd like to talk about them."
- Don't be put off if they don't want to take up your lead. You may need to be quite resilient and single-minded, and state directly that you want a conversation about this. 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. Equally, we all have to face that our lifespan is limited.
- If the other person tries to push the conversation too far away from where you want it to go, try and bring it back.
- But listen to the other person. If you show that you are listening to them, it's more likely they will listen to you.