

## Individual viewing of the public facing video



### Introduction

- This short video is for people who are living with progressive illnesses, and who want to plan ahead and talk with their family or close friends about what's important for them if their condition worsens.
- This short video is also for people who are well just now but want to plan ahead and talk with their family or close friends about what's important for them if they get a serious illness in the future.
- It can also help people, who care for someone with a long-term illness or frailty, know more about what might happen and what can help. This includes family carers and caregivers in care homes.
- The video talks about how people's health changes as they get older, frailer or ill. These changes over time are called trajectories.
- The information is based on detailed research with patients, families, doctors, nurses and other health and care professionals about people's experiences of living with declining health and dying.
- It is produced by a team of health professionals who care for people with many different life-limiting illnesses.
- The video has some ideas and suggestions about how to plan ahead and what professionals can do to help people. We recommend that you talk to your own doctor, nurse or carer about what this means for you. Each country has different legal requirements about health and care decision-making. Everyone is different so it is important to speak to someone who knows you and can help you and your family.

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### Some people find it helpful to think or talk about these questions after they watch this video:

1. Do I know enough about my own health or the health of the person I care for?
2. After watching this video, what questions do I have for myself, my family, and the people who care for me (such as doctor, nurse, or professional caregiver)?
3. Who do I trust and could talk to about any worries and concerns I have since watching this video?
4. What really matters to me? What/ who brings me help and support when I am not feeling well?
5. What kind of things/events do I want to avoid? What causes me fear or worries in daily life?
6. What could I do myself to be more in control of my health and care?
7. Have I thought about choosing a few trusted people to make decisions about health or money/property if that is needed in the future? Do they know what I want and what they might need to do for me? Have I written my wishes down clearly in an advance statement or another legal document like a 'Power of Attorney'?
8. Do I have a will? This may make things easier for people after my death.

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### You may find useful information at:

Patient.co.uk    Good Life Good Death Good Grief  
NHS Inform    Dying Matters



THE UNIVERSITY  
of EDINBURGH



Primary Care  
Reference Group

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**Text of the video** (4min.30seconds)



**This is a short video for people who are well just now, but who might get a serious illness or a life-threatening condition at some time in the future.**

**“ How to live and die well: know more about what might happen and plan ahead as much as possible ”**

One of the secrets to living and then dying well is to understand what might happen for people with different illnesses and plan as best we can.

100 years ago people died from 3 main causes: infections, in childbirth, or in accidents - and these happened relatively quickly. Nowadays, most people will have one of three main types of declining health: cancer, organ failure, or frailty.

Let's look at these 3 main types of illness pattern. A rapid decline taking weeks or months: this most often happens in certain types of cancer. An unpredictable and variable decline taking months or years: typically with longer term lung or heart problems (sometimes called organ failure). Or a longer gradual decline, most often found with the general frailty of older age or dementia. It is important to remember that the future is always a bit uncertain, and new health problems may develop over time.

But getting seriously ill isn't just a physical experience. It's a 4-dimensional one just like normal life: Physical, Social, Psychological, and Spiritual. These other dimensions may be more important to a person and their family than physical problems like pain.

In the “rapid illness journey”, typically with some cancers, physical decline happens more predictably. Some people find themselves more alone or isolated as their physical health declines, but there are certain key times when people might have more anxiety and when questions about the meaning and purpose of life can be common. This may be around the time the cancer is diagnosed, when getting home, or if cancer returns after treatment. So knowing about these common patterns and experiences allows us to prepare in advance and get better support to minimise distress in all these aspects of life.

Looking at the more variable illness journey of organ failure, there are times when people get a flare up of their condition and have to be admitted to hospital or need more care at home. This can be very worrying, and bring social problems at the same time. Spiritual concerns like “what does all this mean” in this sort of illness pattern may come at any time. So preparing and planning in advance to cope with these unpredictable events can make a big difference to how people cope.

Finally, the gradual decline is typically found in people with frailty or dementia. Research shows that non-physical aspects – social support psychological, and spiritual wellbeing, frequently decline long before the person dies. This means that we should try hard to help people and their carers stay in touch with family and friends, and share their anxieties and worries with people close to them and health professionals so they can live well. Talking and planning helps people get support to do the things that are most important for them, and keep as much of their independence and sense of meaning and purpose in life as possible.

Everyone dies, we will all die even if we are feeling well now. Serious illness may suddenly tap us on the shoulder or creep up on us gradually. To know about these patterns of declining health in advance can help us deal with the different challenges that we will all face one day. We want to live and die as well as possible whatever happens.

It's good to think ahead and be prepared. Then we are most likely to live life to the full, and in due course have a comfortable and dignified death.