

## Showing the how to live and die well video to a public group



You may wish to show this video to a group of people to help you talk about living and dying well.

We suggest you watch the video once all the way through, and then again, pausing it at various points for some discussion.

This information sheet gives you lots of advice on how to help guide a conversation within the group – when to pause the video and suggested questions you might ask to start people talking.

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### What does running a session involve?

#### 1. Introduction

We suggest that if you are using this video in a group situation that you start with a brief introduction such as:

*“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”*

#### 2. Watch the video

We suggest you watch the video once all the way through without stopping. This takes less than five minutes.

#### 3. Pause!

Pause the video when the ‘pause’ screen shows. You may wish to have a brief discussion at this point – or simply continue.



#### 4. Watch the video again – but in short sections

Press play again and the video will continue with another run through of the same video – in this version it is split into 6 short sections with pause screens between each one. At the pause breaks, discuss some of the ideas raised in the video.

Read on for more information about each of the sections, and questions we think might be helpful at each stage.

**That’s really all there is to it!**

### More information

#### Important: How to lead a group discussion

As people may be sharing personal thoughts and feelings, it may be useful to establish a group understanding of how discussion will run at the start.

Everyone needs to agree on the importance of not interrupting others and keeping personal information confidential.

If the group is new to each other, an ice-breaker (e.g. short introduction from each person) can help establish rapport and encourage members of the group to speak.

If you have not facilitated these types of discussions before, it may feel uncomfortable at first if there are long silences or if people are reluctant to talk. Silence does not necessarily mean people are not engaged; they may need a few more seconds to gather their thoughts and/or courage to talk.

## Note: Small group activities

If there are a lot of people in the group, you may wish to have some discussion in smaller groups, with someone nominated in each group to lead the discussion and report back with a summary to the whole group after each question. Try to allow time for both discussion and reporting – if you have lots of groups this may take a little longer.

## More resources

At the end of this document is a list of resources you may find useful in preparing or to share with people in the group after the discussion.

Duration	Activity	Group interaction
3 min	Welcome	Introduction
<b>5 min</b>	<b>Watch the video</b>	
1 min	Introduce group activities	“Feel free to ask questions and to share your experience”
<b>1 min 30 sec</b>	<b>Watch section 1</b>	
5 min	Questions to the whole group	<ul style="list-style-type: none"> <li>▶ So if you had a choice, what would you prefer to die from?</li> <li>▶ So which of the three patterns would you prefer?</li> </ul>
<b>20 sec</b>	<b>Watch section 2</b>	
6 min	Small-group activity	What aspect or dimension of living and dying do you think is most important to you?
<b>40 sec</b>	<b>Watch section 3</b>	
6 min	Questions to the whole group	<ul style="list-style-type: none"> <li>▶ So what does this video tell us about dying on this rapid trajectory, typically of cancer?</li> <li>▶ Do you see this true in people you have known or know now?</li> <li>▶ Which dimensions might be especially important for you?</li> </ul>
<b>40 sec</b>	<b>Watch section 4</b>	
10 min	Small-group activity	<ul style="list-style-type: none"> <li>▶ What have you learnt here about people with advanced heart, lung or liver failure?</li> <li>▶ Does this tie in with any experience people may have had?</li> <li>▶ How can we get support in advance of these unpredictable events as well as at the time they happen?</li> </ul>
<b>40 sec</b>	<b>Watch section 5</b>	
10 min	Small-group activity	<ul style="list-style-type: none"> <li>▶ The video suggests that for people who are getting more frail sometimes issues relating to their family and anxieties about losing their independence may cause more problems than the obvious physical one of being weaker and less able to manage without help. What might be the big anxieties or worries of people with gradually declining health?</li> <li>▶ How can we help people stay healthy and maintain social contacts and share anxieties?</li> </ul>
<b>43 sec</b>	<b>Watch section 6</b>	
10 min	Small-group activity	<ul style="list-style-type: none"> <li>▶ Summary and action point: So it's good to think ahead so we can maximise the time left. We often think that people may not want to plan ahead, but research shows that if people are gradually encouraged and given time to do this, over 80% would really like to do it<sup>1</sup>. Who would you like to help you get started with this so that a plan is in place before it's even needed? (for you, or for some of your relatives living with a chronic condition)</li> <li>▶ How would you like this to be done?</li> <li>▶ How might this be different for other people?</li> </ul>
3 min	Closing the session	Thanks Take-home messages (x3)
<b>Total 65 min</b>		

## Facilitation support document

The next part of this document is intended to help guide you through the session. You may wish to make notes on this yourself with any additional thoughts or comments.

Text in **RED** below are some additional notes that may help.

### Watch section 1



#### Video Text:

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.

PAUSE AT 01.27 

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#### So if you had a choice, what would you prefer to die from?

Someone will probably say "I'd like to drop down dead or have an accident". But then you can explain that only around 10% of people die suddenly like that nowadays. About 80-90% die with a progressive illness. This means that there is time to think about the future.

#### So which of the three patterns would you prefer?

Highlight the advantages and challenges of each pattern of declining health as group members make suggestions. For example, people may think they'd like the faster physical decline of the first trajectory and find the unpredictable nature of others more challenging. Other people may appreciate the 'early warning' signs of going out less and becoming more socially isolated but find it challenging about how to spot and react to these. There are no right or wrong answers to this question and people's responses will vary based on their own experiences and expectations.

## Watch section 2



### Video Text:

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.

PAUSE AT 01.45 

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### What aspect or dimension of living and dying do you think is most important to you?

Listen to what people say and give each person time to reflect and respond if they want to. Try to illustrate that for some people it may be physical aspects; for others, it may be social contacts, such as relationships with people important to them.

For others, it may be psychological concerns; people often have worries and fears that they may find it hard to share.

For some people, it may be some deeper issues around meaning and purpose of life or to do with a religious belief or something important in their family or culture.

For some people, it may be all of these things and they may vary at different points.


The point to establish is that what matters most may be different for different people at different times and we should always consider how different people, including ourselves, are affected if we get a serious illness. Relatives and friends can also experience changes along these four dimensions at various times. These changes can be very similar to those experienced by the person with the illness or different.

## Watch section 3



### Video Text:

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.

PAUSE AT 02.25 

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**So what does this video tell us about dying on this rapid trajectory, typically of cancer? Do you see this true in people you have known or know now?**

Facilitate a free discussion around the challenges that people might face. If no one shares information about people they know, you can draw on media representation of dying from cancer (e.g. often considered tragic, sudden or unexpected).

**Which dimensions might be especially important for you?**

Here it is important to listen and enable people to reflect and share their thoughts and feelings. If you can, have people explain why it is important to them.

## Watch section 4



### Video Text:

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.

PAUSE AT 03.08

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**What have you learnt here about people with advanced heart, lung or liver failure? Does this tie in with any experience people may have had?**

People may have less understanding and experience of dealing with serious heart problems, lung problems (COPD), liver or kidney (renal) failure. People tend to have heard more about dying with cancer in the media.

So sharing of information is helpful to understand the likely issues. If no one offers information, you can guide discussion about how living with unpredictable changes in one's health compares to the previous discussion.

**How can we get support in advance of these unpredictable events as well as at the time they happen?**


Starting a care plan with the GP, a community nurse or another health or care professional is a good way of discussing and documenting what each person wishes to happen and would not want done. This might include thinking about what should happen in certain situations (eg being admitted to hospital or some treatments like tube feeding, ventilation or cardiopulmonary resuscitation (CPR)). This will allow the professional to share the person's wishes and care plan with the emergency services and hospital staff. It is also important for people to share their thoughts and wishes with others close to them, such as family members. You could also ask the group if anyone has done this before, either for themselves or for someone they know. You can also discuss how not everyone may wish to make such care plans in advance.

## Watch section 5



### Video Text:

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.

PAUSE AT 03.48 

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**The video suggests that for people who are getting more frail sometimes issues relating to their family and anxieties about losing their independence may cause more problems than the obvious physical one of being weaker and less able to manage without help. What might be the big anxieties or worries of people with gradually declining health?**

Answers are usually about getting dementia, moving into a care home, or being a burden to their family. It is important to raise awareness on the importance of social / family support in such conditions.

**How can we help people stay healthy and maintain social contacts and share anxieties?**

We can help as individuals and also as members of voluntary community organisations to support people, who are living with increasing frailty or dementia. Talk about ways of doing this.

## Watch section 6



### Video Text:

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.

PAUSE AT 04.31 (end)

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### Summary and action point:

**So it's good to think ahead so we can maximise the time left. We often think that people may not want to plan ahead, but research shows that if people are gradually encouraged and given time to do this, over 80% would really like to do it<sup>2</sup>.**

**Who would you like to help you get started with this so that a plan is in place before it's even needed? (for you, or for some of your relatives living with a chronic condition)**

There is no best way for everyone to do this but there are some ways that have been shown to be more effective for those who wish to write care plans. This includes having the time to think about and discuss one's concerns, wishes, and likely future with a trusted person. However, there will still be people who do not wish to do this and it is important to respect this during the group discussion.

### How would you like this to be done?

Allow people to share their thoughts. If people are unsure of where to start with this answer, you can make a few suggestions about who they could talk to, for example, their GP, a close family member, or friend.

### How might this be different for other people?

Point out any differences in the responses that people make. If they are all similar, it can be useful to discuss how some people prefer to have written plans that they can share with their family and friends. Others may prefer to talk about the issues with a healthcare professional first.



## **Suggested resources**

Advance care planning recourses from around the world compiled by HospiceUK:

<https://www.ehospice.com/uk/Home/tabid/1030/tabid/10697/ArticleId/21543/language/en-GB/Default.aspx>