

Card 1

Dying
Matters

BEING CLEAR ABOUT DYING

We asked 1,000 recently bereaved people whether health care professionals clearly told them that their loved one was likely to die.

How many people answered:

“Yes, they were very clear and I understood straight away”?

a. 54%

b. 35%

c. 11%

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The correct answer:

41% of people said they were very clear that their loved one was going to die.

35% said they were somewhat clear.

11% said they were not clear at all.

Dr Lucy Pain, Palliative Medicine Consultant, reflects:

“ It’s reassuring that people usually come away from these difficult conversations with a reasonable understanding that their loved one is likely to die. Ideally conversations about prognosis take place a number of times between diagnosis with an incurable illness and death, with plenty of opportunity for questions to be asked. Unfortunately, it’s often difficult for health professionals to give an accurate prognosis and some of the respondents’ uncertainty may reflect this. But, discussing death and dying is a key skill that all health professionals should receive training in. ”

Lucy’s suggestion:

“It really helps health professionals if you tell them exactly what you want to know. They are grateful for direct questions about death and dying so feel free to ask questions like:

“Please be honest, am I likely to die from my condition?” or, “I’d like to plan for the future. What is the most and the least time my loved one is likely to live?”

TIMELY TALKING

We then asked our bereaved people whether their healthcare professional explained to them that their loved one was dying at the right time. How many people answered:

“Yes, they shared clear information with me at the right time so my loved one and I understood what was happening”?

a. 9%

b. 11%

c. 34%

The correct answer:

34% of people said health professionals shared clear information with them at the right time. Many people said this made it easier to talk about death and plan for the end of life.

9% said that they did not clearly explain early enough, by which point they had figured it out themselves, or were optimistic about their prognosis.

11% also agreed that not being told early enough, which left them confused about what was happening.

Dr Lucy Pain reflects:

“ It can be difficult for health professionals to know what individual people want to know and when, everybody is different and sometimes members of one family have different needs. There is often anxiety from both family members and health professionals about causing harm by taking away hope. In fact, giving false hope can be more damaging by taking away the opportunity to plan and make the most from the precious remaining time. Respondents mentioned how upsetting it was being given ‘false hope’ or information having been ‘sugar coated’.”

Lucy’s suggestion:

“My advice is to talk openly to loved ones and health professionals about what you want to know and when. Address concerns about hope by explaining you want don’t want to make unrealistic plans or goals and tell them what you would like to know.”

DIRECT... OR NOT ?

Our next question was language they would prefer health care professionals use to talk about terminal diagnoses and dying.

How many people told us they'd prefer euphemistic language (e.g. passed away, won't make it, we're running out of options, there's little we can do etc)?

a. 45%

b. 21%

c. 33%

The correct answer:

33% of people said that they would prefer euphemistic language.

45% of people said that they would prefer direct language like 'dying', or 'died'.

21% said that they were unsure, or had no preference.

Dr Lucy Pain reflects:

“Hearing really bad news, for example that you have an incurable illness, is always going to be incredibly painful. It's notoriously difficult to absorb complicated information when being given bad news, so health professionals try to ensure the information they give is clear and concise. Nobody wants to come away from a serious conversation having misunderstood what they were being told. For these reasons, when health professionals need to share a very important message, they try to use very clear language delivered with compassion and kindness.”

Lucy's suggestion:

“If you find certain words difficult and prefer others, feel free to explain this to professionals, friends or family.

For example, “I really dislike using the word die, please can you talk about passing instead?”

COMMUNICATION STYLE

We then asked our bereaved people how well healthcare professionals interacted with them during the final period of their loved one's life.

Take a guess at how many people answered 'very well' or 'quite well':

- a. 21%
- b. 10%
- c. 62%

The correct answer:

62% of people said that they thought healthcare professionals interacted very well, or quite well, with their loved one, them and their family.

21% of people said that they felt the communication was 'average'.

10% said it was 'quite poor' or 'very poor'.

Dr Lucy Pain reflects:

“ Developing relationships with my patients and their family or friends gives me huge pleasure. It's such a privilege to support people through these difficult and very personal times. Everyone has their own individual communication style and preferences which lead to variation in all relationships, including those with health professionals.

Events like Dying Matters Awareness Week are a great opportunity to promote communication skills to health professionals, in addition to empowering people to be more open with friends, family, colleagues and clinicians. ”

Lucy's suggestion:

“Whenever you are talking to someone about death, dying or health in general, remember that you are just two individuals with different personalities and experiences. Whether you are talking to a friend, relative, colleague or professional, being patient and open will always help you both get the best outcome from the conversation.”

IMPACT OF THE PANDEMIC

Our final question was whether our respondents thought the Covid-19 pandemic had changed how they prefer to talk about death and dying.

How many people said that the pandemic made them more likely to prefer 'direct' language, like 'dying', or 'died'?

a. 14%

b. 43%

c. 19%

The correct answer:

19% of people said that, after the pandemic, they now prefer to use more direct language about death and dying.

14% of people said they prefer euphemistic language.

43% said that it's made no difference either way.

Dr Lucy Pain reflects:

“ The Covid-19 pandemic has changed so many aspects of life forever. So many families experienced tragic losses and had traumatic experiences. Because of the huge number of deaths, almost all health professionals had to become much more familiar with caring for dying people and talking about death and dying.

As with most things, everyone is different. The language families and friends use about death and dying has usually been passed on from generation to generation. Although many people became more accustomed to talking about death and dying during the pandemic, I'm not surprised that it didn't have a huge impact on the language used by individuals outside of healthcare. ”

Lucy's suggestion:

If you would like to talk to someone outside your usual social circle following a bereavement, there is support available.

Have a look at these resources from Hospice UK by scanning the QR code, or searching **'I need support with a bereavement'**.



Card 6

EVERYONE IS DIFFERENT

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We asked people to tell us about their experiences and views on discussing care at the end of life with professionals. Here are some of their comments:

“Healthcare professionals were amazing from start to finish.”

“They told us when they knew. They did it in a professional way which supported the family and their time scales matched.”

“They said “palliative care is all we can provide.” I know what that means, but I suppose a lot of people wouldn’t.”

“Information was given which often proved incorrect or sugar coated, they made it look better than it was.”

“No one really ever said it to me – they just assumed it was obvious, I think.”

“Healthcare professionals talk in a different lingo with big confusing words that make you more upset and not understanding what is being said or happening.”

“It’s easy to get caught up in healthcare terminology that nobody understands...being direct eliminates doubt.”

“I like this softer side, it’s a delicate time. I know they need to keep professional, but these softener words are nicer to deal with.”

What do you think about these comments?

Do any of them resonate with you, or an experience you’ve had?

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Dr Lucy Pain reflects:

“ I’m so grateful to the respondents for sharing their valuable experiences. It’s no surprise to see that although there is some positive feedback there is always room for improvement.

I notice that although some people prefer ‘softer’ language, others share their distress when information about prognosis and end of life care hasn’t been shared clearly. For this reason, I encourage professionals to use clear language, delivered with kindness and compassion.

It’s also vitally important that we ask people what they want to know and when, but professionals won’t always get it right so will always be grateful for questions. Nobody should ever feel embarrassed about asking for more information or clarity – if you haven’t understood it then the professional hasn’t explained it well enough.

Don’t forget that professionals can only realistically share important information with their patient and one or two key family members, who would generally be expected to share this information with anyone else who needs to know.

Sharing bad news with friends and family can be difficult. If you aren’t sure how to tackle these conversations, the professionals caring for you will be happy to offer advice and support.”

Lucy’s suggestion:

“If you’d prefer people to avoid words like death or dying, feel free to tell them. Nobody wants to cause distress and as long as everyone is confident what other words mean to you, then it is fine to use them.”