

The DIPEX Charity, PO Box 428, Witney, Oxfordshire, OX28 9EU
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Research on end of life carers highlights need for major improvements in access to support services

A new section of the award-winning experiential health website www.healthtalkonline.org is being launched today (Wednesday, 18th January), based on research carried out by the Health Experiences Research Group, University of Oxford

The new section – “Caring for Someone with a Terminal Illness” – has been made possible through funding from leading end of life care charity, Marie Curie Cancer Care.

It includes video and audio clips of 40 men and women describing in detail the unique combination of hard physical work, conflicted emotions and lack of sleep – as well as the rewards – that can be part and parcel of caring for a partner, parent, child or friend who is dying - a commitment for which many people feel ill-prepared.

Each year, thousands of people find themselves having to care for someone diagnosed with a terminal illness - and they may not anticipate all the demands that will be required of them as their caring role develops and how this role may impact on their life. While a number of contributors express gratitude for the compassionate care they have received, others describe the pain of less sensitive support at this critical time.

“The process of managing a terminal illness can change well-established roles, often reversing the way parent and child as well as partners relate to each other.” said Dr Fiona Barlow, a member of the Research Group. ‘Many carers describe conflicting emotions: wanting the person to remain alive for as long as possible while anxious that they do not suffer - at the same time as wishing for an end to demands that cause such emotional and physical exhaustion.’

“However rewarding the experience of being a carer is, finding support from statutory services can be difficult especially for those who are not aware of the existence of services such as palliative care in the community. What’s more, once accessed, these services can vary significantly in quality and quantity.” she said.

Imelda Redmond, Director of Policy and Public Affairs at Marie Curie Cancer Care, said: “Marie Curie provides high quality end of life care to patients with terminal cancer and other illnesses and most crucially, support to families and carers at the time they need it most. We believe that everyone should have access to these services and that people receive the right care and support at the right time in their place of choice. This section of Healthtalkonline will help carers understand that they

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are not alone and help them overcome the barriers that exist in preventing people having a good death surrounded by their loved ones.”

The new section can be viewed on:

http://www.healthtalkonline.org/Dying_and_bereavement/caring_for_someone_with_a_terminal_illness

Case Studies

Cassie, 26, recalls the ‘heavy emotional weight’ of caring for her father who was diagnosed with cancer of the tongue and throat in 2008 and who was sometimes ‘frightened like a child’. She describes her mixed emotions when she realised that he had a stroke while helping him on the toilet just before he died. ‘I just had this wave of guilt that I’d got angry at him and sort of stood there cuddling him, calling out for my mum who was downstairs and couldn’t hear me. That was probably the moment when I felt the most alone, that this was too much. I just thought: ‘He’s my dad and can’t even help me and I’m calling for my mum and she’s not around’.

Dick, 55 describes ‘a wonderful year’, caring for his wife Di who told a friend shortly before the end how she had ‘learned to accept love fully for the first time and it’s just been really wonderful’. But he admitted the experience was ‘utterly, utterly exhausting.... I felt dizzy a lot of the time, my head was buzzing from lack of sleep - and knowing that she was going to die, it was a labour of love but with no positive end in sight’.

Una, 62, says the assumption is often that ‘everybody’s in an ideal relationship, their circumstances are fine and they’re just doing this carer’s thing on top’. Yet, she says, the truth is that ‘your relationship might not be at the highest point it’s ever been you may have feelings that make you quite humble because you don’t like the fact that you’re having them. But we’re only people and people do have these feelings.’

Henry, 63, says that the nurses who helped him care for his partner Jane when she was suffering from terminal bowel cancer, were ‘incredibly nice people’ who were ‘a huge source of strength for myself as well just because of the way they dealt with and talked to me and made life seem normal’.

Heather, 66, describes how she was able to confide in nurses about her husband Bill’s difficult behaviour without being made to feel disloyal. ‘We had such a close relationship that I was able to sort of tell them. And they sort of never said anything bad about Bill, but I just knew that they knew that he wasn’t always easy.’

Jacqui, 60 caring for her husband dying of chronic obstructive pulmonary disease, describes how ‘it was a nightmare trying to get supplies off them (district nurses)’ and how they’d only do tasks they were supposed to do - such as flushing through a catheter - ‘if I asked them’.

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Roger, 59, who kept detailed notes on the care of his wife, Teresa, during her terminal illness, felt he was ignored or at best tolerated by hospital staff - except when 'they suddenly found things had gone wrong because I actually represented continuity.... I had seen where the breakdowns in communication had occurred, where the notes had gone missing for a time or somebody had said something and not put it in the notes.'

Note for editors:

www.Healthtalkonline.org is an experiential website based on qualitative research led by experts at the University of Oxford and published by the DIPEX charity. It is funded by a wide range of statutory bodies and charitable trusts and is recognised by the Department of Health and many other professional organisations.

The website, which recently celebrated its tenth anniversary, has more than a million hits a week and two million unique visitors every year. They log on to watch video and audio clips from interviews with over 2,000 people about their experience of more than 70 health conditions.

Marie Curie Cancer Care is one of the UK's largest charities. Employing more than 2,700 nurses, doctors and other healthcare professionals, it provided care to more than 31,000 terminally ill patients in the community and in its nine hospices last year and is the largest provider of hospice beds outside the NHS. The charity provides core funding for three palliative care research facilities and supports palliative and end of life care research through its project grant funding streams.

The right to die in place of choice

Research shows around 65 per cent of people would like to die at home if they had a terminal illness, with a sizeable minority opting for hospice care. However, more than 50 per cent of cancer deaths still occur in hospital, the place people say they would least like to be. Since 2004 Marie Curie Cancer Care has been campaigning for more patients to be able to make the choice to be cared for and die in their place of choice.

To interview a carer who has taken part in the research, or for further information, please contact Graham Shaw at graham.shaw@dipex.org.uk or mobile 07799664371.

For information on Marie Curie Cancer Care please contact Alex Holdaway at alex.holdaway@mariecurie.org.uk or 0207 5997702 or mobile 07884311035.