
MEDIA RELEASE

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'We found out about palliative care too late for my dying husband'

'It is absolutely vital that we provide appropriate care that relieves suffering,' says Katrin Den Elzen, whose husband Mark died four and a half years ago.

Mrs Den Elzen has decided to share her story for National Palliative Care Week, this week. The WA Minister for Health, Dr Kim Hames, will launch the week tomorrow at the Annual WA Palliative Care Breakfast.

Mark was 42 years old when he suffered massive strokes as a result of a brain cyst.

'From that day on, Mark's life was hanging by a thread while the horrible truth about his condition slowly began to unfold,' said Mrs Den Elzen.

'This beautiful man was locked in his body, unable to speak or move....it was terrifying. Over the ensuing 8 months I would go through an extraordinary emotional rollercoaster ride while Mark underwent 6 brain surgeries in as many months along with numerous other procedures.'

'Mark experienced extreme pain lasting months at a time. I felt his pain was not well treated. The information was incomplete and confusing. The pressure on our family was nearly unbearable.'

After 7 months Mark received an assessment from a palliative care service.

'The doctor spelt out all our options very patiently and sensitively....Mark was immediately given appropriate pain relief and was pain free for the first time in months. We decided Mark should be transferred to Murdoch Hospice, where he died in a peaceful atmosphere a week later.'

'Losing the man I loved, the father of my young children, changed my world irrevocably, but you learn to move on in life.'

'The support of the palliative care providers has been very important.'

'Really, we found out too late about palliative care. Mark lived in pain and distress for too long. I wonder if Mark's journey, our family's journey, might have been very different if we had understood earlier the end of life care options that are available, and his doctors had had the skills to communicate them to us. He might have had the care he needed much earlier. I hope telling our story can help others understand the issues. Communication is the key' she said.

'Many people at our stage in life, young and active, with children, a growing business, plans for the future, don't ever think about what happens if things go wrong.'

'When they do, you naturally do absolutely everything to fix the situation, but Mark's circumstances show that it's important for everybody to contemplate, discuss and put into place what we want at the end of life,' said Mrs Den Elzen.

Will Hallahan, Executive Officer of Palliative Care WA Inc said National Palliative Care Week aims to equip the entire community with the information and skills they need to help deal with the problems often associated with the end of life, dying, death and bereavement.

'Katrin Den Elzen's story shows that if people don't have that knowledge, if the broader community and everybody in our health system aren't aware of all the options, people can, unfortunately, live in pain and distress and fear, and they don't need to,' Mr Hallahan said.

'Supporting people and families at the end of life is a role for the entire community.'

'Services are available but they only provide a part of the care and support people need,' said Mr Hallahan.

Mr Hallahan is available for interview on 0412 412 532.

Katrin Den Elzen is available for interview on 0412 803 486.

Information available at <http://www.palliativecarewa.asn.au/pall-care-week-2009.php>.