

Personal Experience of Death, Dying & Bereavement

A talk by John Crowter-Jones
at the
'Dying Matters in Devon' Conference
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I feel I must tell you a little about myself. As you probably can see I'm quite elderly, well only in my mid-80s. I've had many experiences over the last 75 years of seeing people dying, strangers as well as members of my own family.

I also have a great deal of experience in caring as my mother was a semi invalid, and I spent more than 12 years as a carer for my wife, Peggy, who developed Parkinson's Disease. I am very sorry to say that my wife died in January 2009.

During her last two or three years life was extremely hard. I was her main carer. I had some help through Direct Payments and used private carers.

My own health deteriorated a lot during that period as her health worsened and also dementia set in. For the last 12 months of her life I found it extremely difficult to persuade her to take tablets or eat any food.

She was taken very ill at home 2 days before she died. I called an ambulance and she was taken to the Royal Devon and Exeter Hospital where they diagnosed pneumonia. By mid-morning the next day I was called in. The duty doctor and a consultant asked me to walk down the corridor with them so they could discuss my wife's condition. They then explained to me that they were proposing to put my wife on what they called the Liverpool Care Pathway.

I had never heard of the Liverpool Care Pathway before. They explained to

me that it meant they would be discontinuing giving her any tablets or medication of any kind and also discontinuing trying to persuade her to eat some food. They said they were doing this because they said if she survived her life would be unbearable. I was asked to give permission for this to be carried out. The doctors also explained that they would be instructing the nurse to give comforting injections during the period so as to minimise any pain. As I had never heard of the Liverpool Care Pathway and respected the doctors I gave permission.

I have gone through some very trying times since then as I felt that I had been instrumental in ending my wife's life. This caused me a great deal of grief, in excess of the normal grief which I would feel anyway as we had been married 57 years, as well as having worked together since we married.

In addition to the grief I also had heart problems. My health improved during last summer, but last autumn I was admitted to the Emergency Medical Unit one Saturday morning and ended up in the same bay where my wife died. The doctor did try to transfer me but there was no other bed available. I was diagnosed with pneumonia and was in hospital for a week. In the following months I was seriously ill, and at one point I was re-admitted to the hospital and my sons were called.

When I was preparing what I was going to say today I found on the internet a leaflet headed *Coping With Dying: Understanding the changes which occur before death* from the Marie Curie Institute which is brilliantly written and explains so much. I was also given second leaflet from the Marie Curie Institute called, *Relative/Carer Information leaflet Liverpool Care Pathway (LCP)*. I now realise how the doctors' decision was arrived at and that I was not personally responsible for ending my wife's life.

A patient is only put on the Liverpool Care Pathway when the doctors consider that the patient is not likely to survive for 72 hours. I now realise I was not responsible for ending my wife's life. I have also been able to convince my grandson, who is a graduate from Oxford, that I was not guilty of giving permission for my wife's life to be terminated. Now I

have shown my two sons the *Coping with Dying* leaflet and talked with them about the actual process we all feel very much more comfortable with what was done.

I would like to pay tribute to the duty staff at the hospital as no one could have been more kind or helpful, particularly a young nurse who looked after my wife throughout the whole period until she died

Dying is something that we all have to face whatever our stature in life. I don't think it should be so difficult for doctors to talk to a patient's relatives about final days of their loved one's life. This could make the actual dying process very much easier to bear. This subject should never be taboo so I hope in the future general practitioners and consultants will be much more open about this subject.

To conclude I am offering some suggestions which I hope will benefit carers and relatives in the future:

1. The first suggestion is when a patient has an incurable illness I feel that the Liverpool Care Pathway should be explained to the nearest and dearest before the final days of the person's life.

For instance, eight months before she died my wife had pneumonia. I was told then it was quite a serious thing for anyone with Parkinson's Disease or any of these long-term neurological illnesses. What I'm trying to tell you is that at that time I should have been warned pneumonia or any serious illness could be something that she would not be able to fight because of weakness due to the Parkinson's Disease. Had I been given that much information in advance I could have coped with that terrible night in January and the following months very much better than I did.

2. The second suggestion I would like to make is regarding the nearest and closest relatives of the patient immediately upon the person dying. It is that some form of condolence either by someone from the chaplaincy or someone with experience in dealing with dying. The first hour or so while you're getting ready to leave the hospital is probably one of the most difficult times in one's life and any support given then would be invaluable.

I served on the Patient & Public Involvement Steering Group at the Royal Devon and Exeter Hospital. After the death of my wife I suggested that something like this should be thought about and also a leaflet about bereavement and where to get help. I understand that that has now been done, and if so I would like to say thank you.

3. A third suggestion is that the phrase “Liverpool Care Pathway” is only used between doctors and nurses. I did an informal survey with some of my friends and none of them had heard of the “Liverpool Care Pathway”. We joked about it being something to do with “Penny Lane”, but some commented that ‘care pathway’ did not indicate to relatives that the Liverpool Care Pathway is, in fact, end of life care. Relatives are too shocked to take in or want to know about the Liverpool Care Pathway. Using that term does not indicate to them the gravity of the situation or that the doctors have decided that they are dealing with end of life care.

Finally I’d like to thank my family and a very close friend for the help and comfort they have given me over the last few months. I now feel contented and accept the situation as it is.

John Crowter-Jones, FIH, is a member of, and has recently retired as a trustee, of Living Options Devon, a charity which helps people with physical and sensory disabilities, and he sat on a number of charitable and public involvement committees campaigning for improvements for carers, patients and the disabled. He is co-author of *Integrated Care: A Discussion Document* (see www.enjoylivingcontentedly.com).