

BRUSSELS PRESENTATION
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By Helen Findlay

First of all, I would like to thank the organisers for inviting me to speak at this conference today. I am very pleased to be here.

I am speaking as a citizen of the United Kingdom and of Europe – I'm still able to make these two claims, just about! Thank goodness.

What I am going to explain over these 15 minutes is what has led me to be standing in front of you now talking about palliative care; what I have been doing on this subject and still doing and my views on where I see things going, or would like them to go, and why.

Towards the end of 2005, my father was diagnosed with Motor Neurone Disease or ALS. At that time, he was the main carer for my mother who had developed dementia following a stroke. They were both in their 80s and lived together in their own home. They had four adult children, two living nearby and two, including me, living further away in the UK. They had numerous grandchildren and great grandchildren.

My father's diagnosis prompted one of the worst experiences that I have ever had in my entire life. But if it was bad for me, it was absolutely horrific and appalling for him. The disease is bad enough, but it was the inability of health and social care services to get their act together that made it a hundred times worse.

It became obvious to us quite quickly that my father had been diagnosed very late in the progress of the disease. He had been experiencing pains in his legs and at the back of his neck for some years and it was invariably put down to age, arthritis, spondilitus etc. He was losing his appetite or, more likely, his ability to swallow and therefore lost weight. It was obvious to us but not, it would seem, to healthcare professionals.

His treatment after a specialist confirmed that he had MND fell well short of what we had all hoped for and were led to believe he would receive. I said he was diagnosed late and this was borne out by the fact that from diagnosis until my father died was around seven weeks.

What my father went through with the disease and was put through by health services in particular is documented in The Findlay Report. This is a case study that I wrote with members of my family after my father died that covers a four month period and includes a day-by-day diary of what was happening plus an introduction and our recommendations of how things could have been made so much better for my father in his last days of life. A copy of it is available on the internet. We have been sending this report out to individuals and organisations including health and social care professionals, decision makers, academics, government ministers and MPs over the last 8 years. It

has gone across the UK and into Ireland, Australia, Canada and around Europe.

We were so upset, like you wouldn't believe, at my father's treatment and my mother's in the circumstances. I was so furious and still am – it's an emotion that still propels me. I'll give you just one example – there are others in our report. When my father was admitted to hospital for a peg feed operation that his GP thought would help to stabilise him, we thought he would at least get appropriate care while there. Imagine the horror that my eldest brother encountered when he went to visit the hospital shortly after he was admitted to find my father lying flat on his back (absolute no-no for someone with MND) on his own on a hospital trolley in a corridor just off A&E. He was desperately gasping for air – he couldn't move and he couldn't speak as the MND had taken his voice. Nurses were standing around the nurses station some distance away gossiping about what they had been doing with their boyfriends the night before and what they were hoping to do with them that night. I know they were doing this because they were talking so loud that my brother and his wife could hear them. My brother was panic stricken that my father was going to die on the trolley and had to literally bang the desk at the nurses station and demand that the registrar be called to attend to him. He eventually arrived and then the registrar instructed the nurses on what they should be doing. It never ceases to be a surprise to me that irrespective of the reason why my father was admitted to hospital, it wasn't then picked up fairly quickly by people who are supposed to be professionals that he might actually be in trouble here. Why? I think because he wasn't seen as a person but just as a body that was in for a procedure. His life beyond that was of no interest. The fact that he had a terminal illness didn't seem to register. In fact, ignorance of it was rife. Not long after this episode, a hospital nurse asked my sister during a visit what Motor Neurone Disease was, how do you spell it and could she write it down for her. I found out all about it from the internet – why didn't she?

After my father died, with this example and others going round and round in my head, I thought to myself that I had two options: either implode and turn in on myself and let it eat me away or, try and channel the experience and the emotions that came with it to help provoke change.

Change in the way that people with MND are treated and raise awareness of the condition; change in attitudes towards care for the elderly; promote palliative care and change in the way that people whatever their condition are treated towards the end of their lives in whatever setting they may be. I decided to go for change – which has also helped to fend off the other option.

This experience with my father was life-changing for me. I left full-time employment and became self-employed. I felt compelled to devote as much time and effort as I could into improving palliative care as me, using my voice and not on behalf of anyone else or another organisation.

As well as pushing out The Findlay Report and using it as a positive lobbying tool, I joined the service user group at the UK National Council for Palliative Care, a voluntary role. This enabled me to have input into the UK End of Life

Care strategy that was published in 2008. I got to speak at conferences involving health and social care professionals among others and talk about what had happened to my father. I didn't hold back on the descriptions but also used the occasions to engage with people in a positive way. This activity also brought me into contact with the academic side and research into palliative care. As a member of the service user group I was often given the opportunity to take part in research or comment on research papers on palliative and end of life care. One such piece of research was a scoping study reviewing the literature on user involvement in palliative care. The main author of this research was your esteemed conference chair, Sheila Payne. This study looked at and analysed research that had been carried out in this area and identified gaps and discovered that the literature is predominantly written by health and social care professionals with very little written by service users. It also highlighted 'champions' among health professionals as a way that service user involvement could be introduced but also as a way of it falling apart if the 'champion' left. In 2008, the NCPC published an executive summary version of this research and I was invited to write a commentary that appears at the start of the booklet. In this commentary I wrote the following words:

"This report identifies gaps in understanding and analysis of palliative care both from the perspective of users and professionals" and "it highlights what creative and imaginative ways can be found to prompt and support initiatives put forward by service users themselves in the field of palliative care rather than them having to wait to be asked by the professionals for their input."

I decided to put my money where my mouth was to help fill a gap and so I embarked on a PhD looking at perspectives on service user involvement in palliative care. I wanted to explore peoples' views on this subject. The scoping study I just mentioned plays a big role in my literature review – I am using it like a fulcrum to see what was published on this topic before 2005 and what has been carried out since then up to now. I am conducting interviews at the moment with participants. I will be comparing the perspectives of those providing palliative care and those receiving it to identify similarities and differences and the implications these may hold for policy-making in this area and for implementing it. I am discovering that there may well be differences between people who are providing palliative care that initially seems linked to their particular roles. I will be exploring this further. My academic background is in politics – I have an MSc in politics majoring in public policy making. So I bring different perspectives to the research both as a service user and from a political base.

I have been campaigning intensively to try and improve palliative and end of life care for nearly 9 years now. As well as being a volunteer with the National Council for Palliative Care, I am also a member of the Marie Curie Expert Voices Group that has opened up new opportunities to get involved; I am a UK Motor Neurone Disease General Election Champion helping to promote the campaign to give people with MND a voice; I am currently involved with the Cicely Saunders Institute at King's College, London as they develop a Patient, Family and Public Involvement Group.

Putting all this together – my personal experience in particular with my father and my mother and her dementia – if I had time, I would talk in more detail about her experiences including in a nursing home where her dementia was virtually ignored. She was diagnosed with kidney failure and given up to 12 months to live. When I asked about palliative care, her doctor said she was in effect already receiving it, but she wasn't. The nursing home saw palliative care as something that happens right at the end of life. Her death certificate did not mention dementia only kidney failure so another one not showing in the statistics. So with my personal experiences along with my activities as a voluntary campaigner in palliative and end of life care; my research for a PhD, I see the following important elements that need to be developed now and for the future in palliative care:

1. A major recommendation in The Findlay Report was the need for a person diagnosed with a terminal condition to have access to palliative care and have what I call a 'conductor' appointed to them. This is like a conductor of an orchestra who has the sheet music (that is, care plan) in front of them and ensures that the rest of the orchestra (health, social care professionals and all the others) are co-ordinated and playing effectively together in order to produce harmonies. I came to this view because of the various roles that family members had to take on with my father and mother. These roles included being advocates and administrators when dealing with health and social services personnel in trying to organise their visits to my father in particular while he was still living at home – and, as it turned out, we had to perform this role when he was admitted to hospital too. Also, we had to be psychologists in order to avoid treading on toes of professionals who we gathered didn't like being told what to do by certain other professionals who they believed to be below them in the hierarchy or if things were being requested of them via non-official routes even though official routes were too slow to cope with my father's situation. We also had to be researchers and analysts in gathering information about Motor Neurone Disease, mostly from the internet, to help us gauge what was happening with my father and the speed of his deteriorating symptoms and also to know what treatment and care should be being provided by health services so we could request it for him. We were communications and co-ordinating managers – at one point, there were over 40 professionals involved in my mum and dad's care, including consultants, and we were co-ordinating all of them. It was too much. How could we provide the emotional support that both my parents desperately needed when such a lot of time was taken up with all this activity? Another element that prompted this 'conductor' idea was when a specialist palliative care nurse got involved with my father's care in hospital. We brought her in, the hospital didn't. Unfortunately, this was only four days before my father died. But in those few days, she gave us a glimpse of how things could have been. She was appalled at his condition (his mouth care was bad all the way through) and that he was in a general ward in the hospital with no palliative care having been provided. She spent time with my father; she talked to the nursing staff; she talked with me and my family

including my mum and asked how we were feeling – this was the first time during the whole process that anyone had asked us how we were coping. She showed us various things we could do to comfort my father for instance, how to calm him if he had a spate of coughing or started to choke. If only she had become involved even a week earlier, then our experience and my father's would have been so much better. I ask myself: why didn't anyone – from consultants to registrars to nurses to speech therapists to healthcare assistants - come to this conclusion themselves and bring in palliative care?

2. The role of service users and their families, carers and significant others having a role as part of the care team needs to be properly recognised. A person is going to be living with the condition that they have for the rest of their lives however long that may be and so their living conditions involving housing, financial status, familial relations for instance are all vital elements of their care and not just an emphasis on pain relief and doctor's appointments. It can't just be lip service. The conductor would work very closely alongside them.
3. A recognition that people like my parents who were married for 62 years come as one package and should be seen and treated in that way and not just as two individuals presented with distinct and separate care deals that cannot work together. Palliative care should treat them as a whole and not separately.
4. The attitudes we bring towards the elderly and how we care for them particularly when they are coming towards the end of their lives needs to undergo a sea change. There is increasing longevity among populations around the world and the implications need to be addressed sooner rather than later.
5. Palliative care is not an extension of healthcare, it is of a different order. It needs to be approached in a different way. There needs to be a mindset and cultural change in healthcare and wider to provide the space for palliative care to be recognised and utilised effectively and involving all concerned, recognising that people are more than a collection of symptoms, that we are complex human beings with many facets to our lives that need to be taken into account when we are moving towards the end of our lives.
6. Lastly, the role of social media in spreading awareness but also helping to change behaviour and mindsets and encouraging engagement. I use twitter extensively. I find out from it, for instance, what latest research is going on in palliative care as some of it gets posted up by academics. It gives me the chance to not only follow clinicians and consultants that are on it but also to engage in twitter conversations with them. The barriers of desks, white coats and deference are not there – on twitter, everyone has 140 characters to put forward a message which is a great leveller. You can also find bereavement support on it; people with life-limiting illnesses post up blogs and there is a fairly large MND community on there sharing information on the latest research and campaigns as well as helping with advice.

The thread running through all these 6 elements has three strands to it: communication, communication and communication – the greatest of these is

communication.

I will be campaigning for better palliative and end of life care for everyone regardless of their condition for the rest of my life if that's what it takes. There has been some success – one of my father's consultants picked up the baton that The Findlay Report threw down and used it to provoke changes at the hospital for people with MND. Two years after my father died there almost to the day, the hospital opened an MND clinic in the grounds for in-patients and out-patients including an advice and counselling service for families and significant others.

As I sat holding my father's hand in his last hours, I promised him that I would not let the way he had been treated stand and I would do everything I could to make it better for others. I intend to keep that promise.

Thank you very much.