Speaking Up – a family's story

Debra Hazeldine MBE shares her family's story and why speaking up is so important for the benefit of patients and families.

Seven years ago, Sir Robert Francis published **the Freedom to Speak Up Review**.
Freedom to Speak Up Guardians were a recommendation of Sir Robert's review, which was instigated because his inquiry into the tragedies at Mid Staffordshire NHS Foundation Trust found that workers felt deterred from speaking up because they feared for the consequences when they did.

Debra Hazledine's mother lost her life at Mid Staffordshire NHS Foundation Trust. Debra, along with others, campaigned for many years from 2006 on to, in her own words, "search for answers and give my mum a voice". Not only did the Inquiry and report come about, but Debra was awarded an MBE in December 2018 for services to patient safety in Staffordshire.

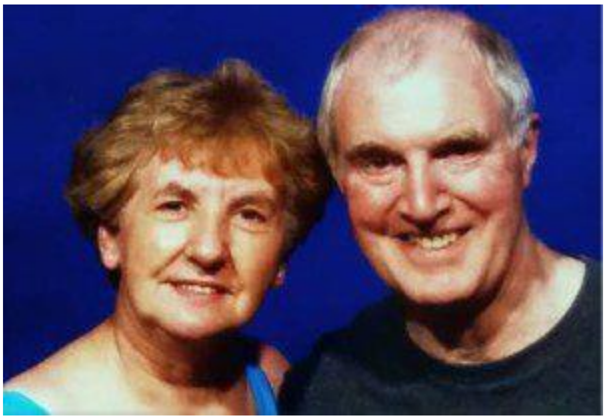
Debra was presented with her MBE at Buckingham Palace in February 2019 on a day that was coincidentally her father's birthday. And it is her father who is the other side of the story Debra tells in her blog below.

As you will read, the terrible experience Debra went through when losing her mother was in stark contrast to the kindness and compassion she experienced when her father died. Both in similar clinical settings in the same part of the country, albeit years apart.

As she so eloquently puts it, "I have over many years tried to give my deceased Mum a voice and now I felt just as passionate about trying to give my Dad a voice also."
Debra's account of her experiences provides an important reference point for the Freedom to Speak Up movement. Her story shows why speaking up is so important. By listening and following up, we can drive change and foster improvement for the benefit of patients and families.

In Debra's words, "So very many people have and continue to work incredibly hard to ensure lessons have been learned from Mid Staffs. Thank you to each and every person that is enabling myself and my family to continue to have ongoing hope for the future."

Debra's story was first shared as part of Speak Up Month in October 2020



Speaking Out

by Debra Hazledine MBE

I never wanted to be a patient safety campaigner. I was extremely happy and contented with the life I was living surrounded by loving family and friends. That life vanished in 2006 and my world crumbled and looking back now over a decade later there was simply nothing more I could have done, although I will always feel that I let my Mum down and should have been able to keep her safe, as she had done for me every day of my childhood. I was a daughter who was desperately trying to support her Mum in a clinical, hospital setting, and it was so very distressing.

My lonely Mum, Ellen Linstead, died aged 67 in heart-breaking circumstances in Mid Staffs hospital. A small District General Hospital in the West Midlands. From the outside it looked like any other local District General Hospital. Somewhere people pass every day whilst going about their busy lives.

What I witnessed on those wards and the unnecessary suffering and pain that my Mum endured before losing her life I will take to my grave, carry with me always. My Mum was called a bed blocker, she sat and cried, she just wanted to go home. On one occasion before even entering the ward I could hear my Mum screaming. I dropped my bag and I ran to her, she was half on the floor and half on a commode and in so much pain. She grabbed my hand and said, "Please Deb, don't let me die in here," and I failed, categorically failed to be able to prevent her suffering and keep her safe. Something that to this day that haunts my every waking and sleeping hours.

After my Mum's death when we thought the worst had happened and the despair, we felt could not increase any further it then did. We were told that we would not be able to see my Mum at the undertakers due to the hospital acquired infections that she had. My Mum died of C-Diff. I desperately needed to be able to see my Mum out of that hospital setting even if only for a few short moments.

I saw my Mum briefly and my final memories are of her head protruding from a body bag. I was unable to hold her hand or kiss her forehead gently, but I needed to be with her at the very end, however bad it got. I needed to be able to say I was so sorry I couldn't keep you safe I am so sorry I let you down.

I lost my inner peace that day and I did not want other families to know this pain, a pain that knows no limits, a pain that does not diminish. I just had to try and speak out and give my Mum a voice. The voice she desperately needed and no longer had.

Trying to speak out in a clinical setting when you are labelled as an overprotective daughter who is just so very worried about leaving her Mum alone is mortifying. The consultant had to write in the notes that I could visit at any time to support my Mum, support she desperately needed because of the abuse I received. Hearing someone say doesn't she know the damn visiting times when I was so distressed, worried about my Mum crushes you as a person. Trying to speak out as a patient in a clinical setting in your nightclothes when feeling vulnerable, unwell, is incredibly scary and can feel impossible. I physically shudder when I think how much more my Mum would have suffered if she had not been supported by her family. I had so many sleepless nights worrying about what was happening to those who have no one, only the system to be their advocate when they are at their most vulnerable trying to be heard, when the system has lost sight of the patients.

After her death we were given my Mum's belongings back to us in a bin bag covered in faeces. Her dressing gown which we had been told had gone for cleaning, her glasses, clothes, all covered in faeces. All had to be thrown away. Then my Mum was returned to us in a bag marked highly infectious. Painful memories to live with. Over many years people have asked why I spoke out, why I raised valid concerns and how I kept going for so long. Because I did not know how I was going to live knowing other loved ones could suffer unnecessarily and die and another daughter would have mine and my Mum's final memories.

I then spent far too many years meeting other distraught families who had the most distressing memories too. From 2005 to 2009 between 400 and 600 more patients died at Mid Staffs FT than would have been expected. The high mortality data being a red flag to go and check. To actually open a door, enter a ward and see and hear the patients and their family's experiences. Cost-cutting and prioritising of targets and obtaining foundation trust status sadly resulted in the patients and families becoming lost, and not always a priority in a care system, that had in parts, become immune to the sound of pain.

The Public Inquiry heard from 250 witnesses and over a million pages of documentary material. A "story" of the appalling unnecessary suffering of hundreds of people. A lack of care, compassion, humanity and leadership. The most basic standards of care were not observed. I was one of those 250 witnesses that gave evidence on oath. No one's precious loved one's final days, weeks, hours should need to be included in the contents of a Public Inquiry.

Thirteen years later I am once again in a local clinical setting with a precious loved one. The sounds of the ward intermittently seep into the side room, bringing back stark memories that

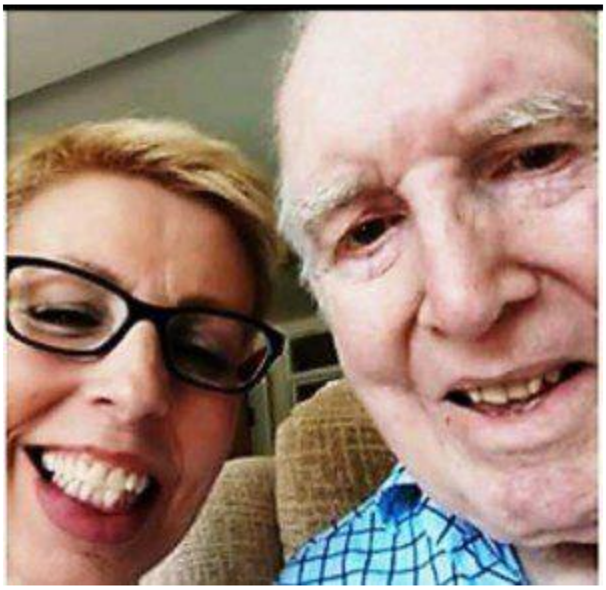
I have struggled with for many years, and will always struggle to live with. I am sitting with my wonderful Dad, Tom Linstead. An 83-year-old gent who has spent the last thirteen years of his life desperately missing his wife Ellen. A father, brother, grandfather, uncle, husband, now widower, and most importantly to me my lovely Dad. His entire life spent well, full of love and kindness.

Visitors pass by his room door, busy staff supporting patients. Catering staff are once again doing their rounds offering food and fluids to anyone who would like them. The atmosphere is calm and friendly and incredibly professional. There are no shouts for help unanswered, no buzzers ringing out for lengthy periods. I cannot help but contemplate how different that last decade and beyond my life could have been if my Mum had been on this ward, in this room all of those years ago, and things may have been so different. These thoughts bring tears to my eyes.

The nursing staff are professional, incredibly supportive and kind. They smile knowingly at my family as they pass to and from my Dad's side room. The consultant has entered the room several times over several days and asked if Tom and his family need any further support, do we have any questions, do we need absolutely anything? He advises he is on the ward and if we need anything please do not hesitate to approach him. If he is not on the ward, he is always contactable, and we should not hesitate to do so.

This kindness gives me and my family so much comfort, the reassurance that my Dad matters, and so does his family, it is difficult to really put into words, but so important that they are shared. End of life final experiences for patients and their families are just that, final, not able to be repeated. Its why in my humble opinion they are so important to be supportive, peaceful memories for all. Healthcare staff can't possibly remember every interaction with their patients, but I promise you patients and families will remember you. The impact you have on their lives. You are there at times of devastation, sadness, sorrow and times of joy and celebration. Every interaction with the patients has a ripple effect. It impacts on the lives of their families, friends, neighbours as well as their own.

Healthcare assistants, nursing staff and catering staff enter the room at various times, very quietly, they support my Dad and his loved ones sitting around his bed. Personal care is attended to, pain relief, full explanations of what is and will happen is given, so very reassuring for the emotional worried faces siting around the bed. Everyone is supported. The ward is clean, the side room spotlessly clean, comfy chairs are available around the bed, family are told they are able to stay, come and go as they wish, there are no visiting time restrictions. This is a setting in which a patient can spend their final days, hours, with dignity and respect.



My Dad is in Royal Stoke Hospital, The University Hospital of North Midlands Trust and the hospital that merged with mid Mid Staffs now known as The County Hospital. He has a Purple Bow at the end of his bed and on the front of the door to his side room.
The Purple bow scheme identifies patients coming to the end of their lives. The bow is a visible sign for all that this patient and family need ongoing support at a very emotional time. It quietly and respectfully signals to everyone that they need to be mindful and respectfully ensures everyone is aware and understanding around the patient and their loved ones whilst they are nearby.

A small pack is also given to the family with vital information enclosed, letting families know what extra support is available. The very visible signage can also be used in a ward setting. My Dad had a purple bow follow him to a side room after being on a ward for a short period. It was somehow extremely comforting to my family that it followed him.
Food and drinks are continually offered to my immediate family, they are made to feel that they are also being cared for, looked after to enable them to continually be with their loved one. An empathetic smile from passing staff, a nod from others, ongoing acknowledgement that my family are not alone. It again brings me to tears, this is how it should be for everyone.

As I look down my hand seems small holding gently the larger hand it has held for many decades. A lifetime of memories captured in that moment of hand holding. I am sitting close to my Dad and cradling his hand in mine. A tear falls from my Dad's eyes as his breathing becoming more laboured with each breath. My Dad opened one of his eyes and looked at me our gaze held for a few moments, much is said in that last look between me and my Dad, it is to be the last time we communicate. A precious moment that we both know will need to last for eternity.

I say very gently to my Dad, "Mums waiting, you can go to her now. Hug her from me, tell her I miss her, I love you and will carry you both in my heart for always."
Then the breathing is no more, the room is still apart from me holding my Dad's hand tightly now. My closest family members are with me too. Thirteen years of tears and emotion overspill into the room. Me and my Dad have survived every day of the last thirteen years by taking some days one hour at a time and loving each other. We never once parted without saying we loved each other. We knew more than most that no one is guaranteed tomorrow.
After my Mum's traumatic death, my Dad became the centre of my family's world, but he was never really able to truly live after losing my Mum, his soul mate in such a distressing way.

I have over many years tried to give my deceased Mum a voice and now I felt just as passionate about trying to give my Dad a voice also.

Thank you to all of the staff at UHNM for their wonderful support. The end of life, palliative care team, ward 102 and SAU. Your professionalism, your kindness will never be forgotten.
My Dad received exemplary end of life care. Your staff also cared for me and my family. For me this meant so much because to this day I struggle to be in any clinical setting.
Thank you to the hospital chaplains, you gave so much comfort at a time when it was most needed.

Death comes to everyone, however it's how you die and the memories you leave with your loved ones. Thank you for ensuring my Dad's final days were peaceful and dignified. I cannot say how much this means, to be able to retain peace during and after my Dad's death. Thank you.

Both of my parents died in clinical settings in Staffordshire, over a decade apart. Memories of one haunt me to this day, another gives me peace.

So very many people have and continue to work incredibly hard to ensure lessons have been learned from Mid Staffs. Thank you to each and every person that is enabling myself and my family to continue to have ongoing hope for the future. Having lived through the troubled times at Mid Staffs, I have to date never entered a clinical setting that was anything like that time.

Patient safety is an ongoing journey and change can often feel frustratingly, painfully slow, however I feel it is disingenuous to state absolutely nothing has changed since the Francis reports, because in Staffordshire it has. How terribly disheartening for all dedicated staff to not know how much this hard work is appreciated. As I have stated many times, the NHS's best asset are its dedicated staff. From myself, my Dad and my family, thank you. It does not go unrecognised and will never be forgotten.

Some desperately tried to make Mid Staffs simply about numbers, arguing about how many people had or had not lost their lives. When in fact, Mid Staffs was primarily about mothers, fathers, sisters, sons, daughters, brothers, aunts, uncles, friends and neighbours, their last weeks, hours days. It was their hopes and dreams, plans for tomorrow, precious time they had hoped to be spending with their loved ones. Stopped in its tracks, suddenly, unnecessarily suffering before going from a unit number, to a deceased unit number.

Speaking out for many years was one of the hardest most emotional things I have done. It was not always welcomed; it was not always believed and sometimes my voice did indeed shake. It should never have taken so many years and been so awfully hard to give my Mum a voice. To all who have and will in the future speak out and raise their voices, thank you. You must have the highest support to do so. Because sometimes lives depend on it.

Within the Francis reports, enclosed within the pages are learning for all staff, alongside patients’ final days and their loved one’s memories of these experiences. A report to be read, discussed and always if I may humbly say with the acknowledgment and never forgetting that for some families this was their lives then and continues to be today and tomorrow. To know that these reports have been acted on, taken to heart by Staffordshire healthcare settings is a fitting tribute to all who died too soon.