

Transform MedEd Workshop: Patient Narratives in Medical Education

Narrative 1. "I am at a loss of how I can help her"

Posted by CSPW (as a parent/guardian), <https://www.careopinion.org.uk/879153>

Over 8 weeks ago we were advised by her he GP to make a referral to CAMHS on behalf of our daughter. We did this in the same day. My daughter had been struggling for several months with meltdowns and we reached out to the GP as we were worried about her mental health. She was having extreme panic attacks and they were getting worse by the day, with her waking at night, hallucinating from lack of sleep and having severe meltdowns that would last hours.

We provided this information to CAMHS and the GP. Over the coming weeks my daughter's condition worsened, we had to ring 111 in the middle of the night several times. She became extremely violent when having attacks and it was made worse as she couldn't sleep. We have phoned CAMHS and CAMHS crisis for help and we have received no support at all and we have basically been told it's our parenting. We have gone through a private assessment due to lack of help and my daughter is autistic and has extreme anxiety, we have provided this information to CAMHS to be told they have even looked at the referral yet.

I do not understand what it will take to get my daughter help, she cries asking for help and I am at a loss of how I can help her. The clinicians I have spoken to on my many calls are rude, patronising and impatient. I was advised to just let her fall to sleep when she can, without them even taking into consideration the meltdowns and panic attacks she has to go through before becoming exhausted and falling to sleep at 8am. She gets to a point where she has to have several showers in the early hours of the morning to get the 'bugs' off her or she escapes from the house as she cannot breathe and believes she is going to die. I have spoken to the GP several times, basically begged for help just to be told I need to wait for CAMHS. I have not been provided one single update from CAMHS, I have asked several times about the process just to be told the assessment we have paid privately for will provide direction.

I am astonished how a GP service and mental health department can leave a 10 year old girl going through this ordeal and allowing her mental state to deteriorate. She cannot get dressed, leave the house or most importantly attend school as this is part of her anxiety. A 10 year old girl having panic attacks every single day and night to me is urgent, especially when she's crying she wants to die. I feel let down and I just hope that CAMHS are officially audited and the lack of service and empathy they provide is highlighted. In the meantime my little girl continues to suffer and doesn't understand why the doctors won't help her, at what point do CAMHS class a referral as urgent.

There are several other concerns I have highlighted around obsessiveness and being able to move because her hair touches her and still none of them have been taken seriously.

Narrative 2. "Extremely painful hysteroscopy"

Posted by daffodil86 (as the patient), <https://www.careopinion.org.uk/962527>

I was referred to the outpatient hysteroscopy clinic at West Cornwall Hospital after experiencing unusually heavy menstrual bleeding and pain. A previous ultrasound showed that I had an intramural fibroid, so I was offered a hysteroscopy and biopsy to investigate the position of the fibroid and understand its implications for my future health and chances of conceiving.

The patient information leaflet I received in advance of the procedure left me woefully unprepared for the excruciating pain I would experience. It stated that I could expect mild period-like discomfort which most people tolerate well and advised that paracetamol and ibuprofen could be taken prior to the appointment, giving me the false impression that the procedure would feel no worse than others I had already undergone, such as an IUD fitting or cervical smear.

During the brief consultation I received before undergoing the procedure, I expressed how nervous I was to experience pain, and was told I could have a local anaesthetic. I was not made aware that I could choose to have a general anaesthetic, or reminded that I could ask for the procedure to be stopped at any time. At no point was my gynaecological pain history discussed (I have suffered with Vulvodynia since I was a teenager) or my past experience of sexual assault taken into account (both records I presume can be found along with my patient notes).

When the hysteroscope was passed through my cervix I was hit by an astonishingly powerful searing pain and series of sharp contractions - it felt as if my uterus was full of razor blades. The pain was so strong I thought I was going to pass out, and waves of nausea washed over me – it felt as though my body had gone into shock. I shouted out in pain and was told to keep inhaling the gas and air provided. I realised that the local anaesthetic (LA) was not applied before the procedure began and I started to panic, hyperventilate - and sweat profusely, so I was handed a paper towel to wipe my brow. I told the doctor I didn't think I could bear the pain any longer, but they didn't offer to halt the procedure and carried on. I felt trapped - like this was something I had to grin and bear despite the evident distress I was in.

One of the nurses present bombarded me with questions (presumably designed to distract me) and I was asked repeatedly about the accuracy of my patient information which I felt was entirely inappropriate under the circumstances. I was not given any choice about whether or not I wanted to see the overhead monitor screen which showed the bloody and clouded image of my magnified uterus. Throughout the procedure the doctor did not verbally walk me through step-by-step and explain what they were doing as I had expected, and so I was left with a continual feeling of suspense/not knowing what was happening next. This combination of factors (being in intense pain, seeing blood, being repeatedly questioned, not knowing what was happening) ultimately contributed to the overall stress of the procedure.

When I requested the promised pain relief, I was horrified to be told that the LA could not be given until the next stage of the procedure, and that in any case it would cause an additional scratching pain on delivery. I felt as though I was somehow asking too much, and being frowned upon. I wondered why these details hadn't been

mentioned beforehand, and told them to go ahead and give the local anaesthetic asap; unfortunately it didn't seem to make any difference.

After the procedure was completed and a biopsy taken, I felt so dizzy/weak that I thought I might collapse. I gingerly made my way to the recovery area feeling bewildered and faint. I was offered a cup of tea, but I felt I wanted to curl up into a ball and cry. I was still in a heightened state of anxiety and pain due to the ongoing contractions of my uterus. Incredibly, I was told by the doctor that I'd tolerated the procedure well and given a survey to fill out. A nurse came to take my blood pressure and asked how I was feeling – when I replied that I was still feeling shaky and anxious, the nurse asked why? bluntly, almost incredulously, instead of offering comfort or support. This made me feel as if I were in some way strange or wrong for reacting to the procedure in the way I did.

When I returned home I searched the web to see if anyone else had gone through a similar experience and discovered via the Hysteroscopy Action website that, sadly, my experience is not a one-off; many women all over the country experience intolerable pain during NHS outpatient hysteroscopy, are not fully informed of the likelihood of moderate to severe pain before the procedure date, and are unaware of their options concerning pain relief, which includes being offered a general anaesthetic.

From the moment of my arrival at the West Cornwall Hospital in Penzance I felt I received 'conveyor-belt style' care, with staff superficially pleasant but ultimately indifferent to my suffering. I left feeling traumatised, and the experience triggered a period of low mood, tearfulness and anxiety which persisted for many weeks. I experienced nightmares, and had to take time off work.

I understand that hospitals want to save patients' time and cut down on spending by conducting procedures on an outpatient basis rather than admitting them as day cases, and that a proportion of women will tolerate outpatient hysteroscopy just fine. However, I implore the RCHT to update their information leaflets to reflect the guidance from the Royal College of Obstetricians & Gynaecologists so that all women due for the procedure can make the informed choice that is right for them regarding pain relief, and avoid suffering.

Narrative 3. "Lack of Dignity, Respect, concerns over DNR"

Posted by apusfg46 (as a relative), <https://www.careopinion.org.uk/495403>

My Father and mother-in-law 90 and 88 respectively were scheduled to be discharged after both having been in hospital since Christmas. There was a large care package arranged for them to enable them to be discharged and safe to be at home.

On the Monday morning the hospital beds were delivered to their home and other essential medical equipment. After I had arranged their rooms I drove to the hospital which is only five minutes drive from their home, to see how they were and to give them outdoor coats for their return. On route the pharmacy contacted me for some information and advised that their medication would be with them shortly.

I went to their ward to find the beds already stripped and I subsequently found them in the discharge lounge, the time being 11.25am and they had been transferred from the Ward at 11.00am and 11.15am.

I didn't stay long in the discharge lounge with them as I presumed as their medication was on the way they would be home shortly.

I went back to their home and prepared for their arrival, but at 3.30pm my husband called to say the ward nurse had been in contact with him and advised that his parents were now in the discharge lounge. Eh! No they've been there since before 11.30. He called the nurse back who confirmed they had been transferred at 11.00am and the ambulance should have been there to take them home at 1.30pm.

I called the patient liaison office at the hospital and said that I thought this was totally out of order, the time now being after 4.00pm. The person said they'd find out what was going on and call me back which they did promptly to advise the ambulance would not now be there till 5.30. I expressed my concern that two vulnerable patients were being treated with anything but dignity and they then said they would try to escalate a quicker response.

I made my way back to the hospital and discharge lounge and after parking arrived at about 5.15. Goodness I was met with a very sad sight indeed. My father-in-law was slumped over the arm of his chair, propped up with a pillow, my mother-in-law was looking extremely distressed and when I asked if she was all right, she replied that she had had an 'accident'. The discharge nurse confirmed to me that they had been there since 11.00 am though they had had lunch and dinner. I asked the nurse if she could take my mother-in-law to the toilet. The ambulance crew then arrived at 5.45. They had no knowledge of any previous times and indeed had only just recently started their shift.

I waited on the nurse returning and the ambulance crew then helped my in laws into the ambulance, I made my way back to their house and the ambulance crew then assisted them into their beds, finally they could relax and this would now be 6.10pm some seven hours after leaving their wards. I feel that they were certainly have not been treated with dignity they deserve.

I also want to write about a serious concern over the DNACPR (Not for Resuscitation) form and procedures.

I was taken aback on picking up my father in law from the discharge lounge the ambulance crew opened a letter lying on the table to see it was a Not for resuscitation form.

I knew it very unlikely my father in law would have agreed to this and on closer inspection of the form have found a few discrepancies.

First of all this form completed was I believe obsolete at the time of completion. The patient or any relative had not been involved in the decision to agree to DNACPR and my father in law confirmed that he had had no discussions about this matter. There are no sections on the form marked to say this has been agreed or discussed with anyone.

The reason given on the form is noted - CPR is unlikely to be successful due to: Frailty, Age. I cannot believe that 'age' is a relevant reason.

The form was initially signed by a junior doctor on my father in laws admission when I doubt any observations as to his frailty could have been borne out.

I await your comments on this serious matter.

Narrative 4. "Thank You from the bottom of my heart for everything"

Posted by Lottie21 (as the patient), <https://www.careopinion.org.uk/342482>

I am a 93 year old who has always led an independent and active life so it was a massive change to me when I recently broke my leg and lost some of that independence. I was transferred to Lindsay Ward at the Biggart for my rehab and there begun my journey of excellent care, compassion and above all respect from the staff at the Biggart.

I say staff for all has been equally part of my journey from the domestic who mops the floor to the consultant in charge of my care and of course the managers who must have agreed to the path of my journey.

My 90 year old wife of 69 years had end stage dementia and was a resident in a local nursing home. It broke my heart to not be able to go see her as she was upstairs in the home and the lift was broken but the nurses happily spoke to the staff in the home for updates.

My two daughters live in Australia and despite the ward being busy and the staff being run off their feet it was never too much trouble for them to stop and alleviate any concerns they had over the phone or just update them on my progress.

As I got stronger and almost seeing the light of discharge I was gently woken one night and told my wife was very poorly and had been transferred to Ayr Hospital. One of the auxiliary nurses kindly took me across to Ayr Hospital to be with her and sat with me all night at her bedside offering me support and ensuring I was OK.

We were in a side room and the next day the SCN from Lindsay Ward came to see me and explained my care was being transferred back to Ayr staff so I could remain with my wife and a second bed would be put in the room where we could be nursed together. A few days later my wife and myself were transferred as a pair back to Lindsay Ward where they had created a "double room" for us and we were welcomed back as if part of their family.

The care for my wife was excellent and was evidenced by the fact she never once looked like she was in any distress or discomfort and although she was very thin and frail her skin was perfect.

Most comforting to me was the fact that at night they pushed our beds together to create a double and I was able every night to lay holding her in my arms and reassure her I was there something I had not been able to do for some time since she entered the nursing home.

But it was not only the care for my wife that was at the forefront of the staff's mind and they would offer to sit with or keep an eye on her and encouraged me to take time away from her bedside even if it was just to go eat a meal in the day room.

My wife's condition was deteriorating and my daughters arrived just in time for us both to be transferred to Drummond Ward still at the Biggart. It was difficult for us to leave the staff that not only had I built a relationship with but that I trusted with my now terminally ill wife's care.

This was made so much easier for me though by the SCN from the other ward visiting and explaining things to us starting to build his relationship with us and of course by him also creating a "double room" for use by us and also now my daughters who were sitting with us most of the time.

Once there the excellent care and compassion continued and we quickly came to trust these new faces to us too.

Sadly my wife passed away but we were all by her side and her passing was made easier in the knowledge that she did not suffer and due to the excellent care of staff at the Biggart Hospital it was as stress free as it possibly could have been.

I will be eternally grateful for the care we all received for in the end the staff did not only care for my wife and me they cared also for my daughters.

Most of all I am grateful for the opportunity to have spent the last nights of her life with her in my arms as we had done for oh so many years prior to her leaving for the nursing home.

The support did not end with my wife's passing for to my heartfelt surprise the SCN's also attended my wife's funeral and the nursing staff are now continuing to support me through my grief still as a patient in Drummond Ward.

Thank You from the bottom of my heart for everything.

Narrative 5. "Poor end of life communication and support"

Posted by Backseat Driver (as a relative), <https://www.careopinion.org.uk/944821>

My partner had MND for five years and the type was Progressive Muscular Atrophy. He spent 4 days in Neurology Ward 53 in November 2021 learning how to use a Non Invasive Ventilator to improve his breathing. He was well treated in this ward, nurses understood his condition and treated him accordingly. I could come and go as I pleased and was allowed to sleep in a bed beside him, I did this a few nights, on the nights that I went home he was always fine in the morning. The pressure and effects of Covid were reduced in the Hospital, things were getting better.

Due to the progressive, wastage of muscles in MND the last two years had been a struggle and the previous six months required me to care 24/7. Sleep deprivation was horrendous for us both. He could not move from the neck down, severe pain from joints, constant painful leg cramps, constipation, digestion, fear of choking reducing what foods he could take, poor sleep and nightmares. He also had other health issues, atrial fibrillation and an enlarged prostate which affected him. His voice was weak and he was totally dependent on others for everything and also at the mercy of everybody.

The G.P admitted him to hospital because of a chest infection and initially after a 10 hour wait he was in ARU5, where again he was treated very well by the nursing staff. He was moved to Ward 7C. I have already had a meeting with the respiratory doctors and the neurologist as I was dissatisfied with his care in the ward and the lack of communication and advice. This meeting identified issues with the nursing staff and I wanted to meet them. I have spoken to the respiratory nurse who has checked that this information was passed on but they have ignored the request.

The nursing staff knew he had MND but did not take this into account when treating him. I stayed with him 24/7 apart from three evenings. I found out the next day, though the nursing staff assured me he would be checked every 30 mins as he could not shout or press a buzzer, that he was ignored. First evening a request for an additional pillow was refused, we never saw that nurse again. Another night his mask was slipping and according to the nurse he did not want it on.....he needed it.

In early December after two episodes of struggling to breath and rapid heart beats, a doctor who I had never seen before said he was dying. I was shocked as I was never told to expect it. He was quickly sedated and put on nil by mouth which I found totally barbaric and cruel. The second day I put water from my fingers onto his lips and he nearly bit my fingers off trying to drink, he was dying of thirst. I requested sponges and a spray to help him. Neither the doctor or the nursing staff had bothered to check him, they should know the effects of oxygen.

I feel after all the care we received from the support groups in the previous two years his last days were spent in agony and terror. No co-ordination between respiratory and neurology to ensure he was treated sympathetically. God help patients who have nobody to help them.

Narrative 6. "My late brother and the late diagnosis"

Posted by EBard (as a carer), <https://www.careopinion.org.uk/798814>

My late brother and the late diagnosis of his idiopathic pulmonary fibrosis

In November 2018 my brother went to his GP complaining of severe shortness of breath in that it was making everyday things very difficult for him to complete. His wife had died of cancer a few months before and everyone thought it was caused by the stress of looking after her. The doctor referred him for a CT scan. By February/March 2019 he had heard nothing from Antrim Hospital so I phoned the hospital to find out the waiting time and was told it would be a year.

I took him back to the doctor as he was getting much worse. The doctor referred him urgently and he got the CT scan in April. As soon as the results were though which indicated pulmonary fibrosis, the doctor referred my brother urgently to the City Hospital respiratory clinic. I phoned the City Hospital after a few weeks to find out how long it might be for an urgent appointment and was told that the request had not been triaged yet. I phoned again a week later to be told the same thing.

After 3 weeks with me phoning every few days, someone eventually had the sense to see that something was wrong as the request should have been triaged within 3 days so she put the request through to another doctor. I was told it could be the summer June/July before he was seen as an urgent referral and meanwhile my brother was getting worse. I spoke to the consultant's secretary to say how bad he was and he got an appointment in early June.

At that appt we discovered that he had IPF since 2015 and it had been highlighted on a CT scan done at that time but had not been picked up at his doctors surgery and no hospital referrals or treatment had been arranged. The staff at the city hospital arranged urgent and immediate oxygen therapy, a trial drug and a care package as well as house visits by OT's and district nurses from both Beech Hall health Centre and the Shankill Wellbeing Centre in Belfast who were very good and very attentive as they realised how seriously ill he was.

Their care and that of the City Hospital chest clinic staff was excellent. His oxygen requirement increased rapidly and the nurse dealing with him was wonderful and so helpful and supportive. She warned me that he wouldn't last long but I realised this myself and had done for many months. Just a few days before he was due to have palliative care, he passed away peacefully at home in September 2019.

I spoke to his GP afterwards who was shocked and apologised and said they didn't know how my brother's condition had been missed 4 years prior. They had been treating my brother for another condition at the time when they thought he had cancer and the doctor thought that with going between so many consultants and different hospitals, information had fallen between the cracks. However, I feel that this oversight was the responsibility of the surgery and the GP/s in that they couldn't have read the CT scan notes which I saw at a later date and it was very clearly stated.

I know that my brother would have died anyway with IPF but he could perhaps have had a few more years of life and been more comfortable and prepared if he'd had the new drug therapy when the IPF was first highlighted by the hospital CT scan in 2015 but what annoyed me was how when the failure of his diagnosis was discovered, all the

doctors and consultants went silent and I could tell by their silence and reticence to discuss the issue that something was wrong. I also think waiting 1 year for a CT scan is scandalous and I also think that there should be some sort of follow up procedures to ensure that referrals are triaged within the normal time frame and allocated to consultants so that conditions can be assessed and appointments given within a reasonable time frame.