

Patient Story, Eleanor Rigby

Interviewed on the 15th November 2016

Story initially passed on by Gill Close, Governor.

Annie Laverty visited EOR at home on Tuesday 15th November 2016 to listen to EOR's experience of emergency care and her cancer diagnosis and prognosis. Key issues summarised below:

April 16 - Oesophageal Cancer – waiting to hear if it was operable. In the meantime NTGH were going to get back to me.

Admitted on emergency into Cramlington for five days on ward 4. Bleed in the oesophagus. Nobody explained it was a bleed from the tumour. Everyone hotly perusing tick boxing. There wasn't anything technically lacking but there big gaps in the way my bad news was conveyed to me. At the time blamed myself – I needed to know and was asking searching questions – it had been just 4 weeks after my initial diagnosis.

My doctor was an older man – his English was good, he was warm but factual, but there were nuances missing and something got lost in translation. Well before visiting time I was told "it's not operable, prognosis is very poor and with cancer you have, your care is entirely palliative"

I asked "is this terminal?" I was told not yet, could be 6 months or less, could be a year or more.

The doctor was accompanied by a woman – I was never introduced to her? She took a seat in the corner and listened. I looked to her at this point, believing she'd come to support me. She stood up, looked at her feet and walked out of the room.

Nobody asked me if she could be there to witness the delivery of such devastating news – nobody asked if I minded? Looking back I really did mind and should have been asked.

Nobody asked to contact my family or checked if I wanted loved ones with me. A few minutes, nurse came in – I was crying and apologised explaining I had just had some bad news - she looked at my notes, said "ah" and then left the room ?

Care came in the health care assistant – I asked if I could contact my family and was told I'll have to check with the sister. Nobody came to see or check on me. They were rushed off their feet.

At the time I was having significant difficulty swallowing – I was been encouraged by the dietician that I would be enjoying full meals in no time at home when in reality I couldn't swallow water. I was aware of staff coming in to my room while I was vomiting in the toilet – there is no way that they could have avoided hearing me be sick and yet no one came to check if I was ok ? They appeared far too busy to care.

This experience would have been bad enough but I also witnessed the poor delivery of bad news for someone else and it brought it all back.

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In the July I developed a blood clot on my lung. It was actually found as a result of scan to monitor the tumour – which was good.

I had been receiving back up treatment to the line in my chest. an anaesthetist warned me I was at high risk of blood clot so I should report anything – I rang oncology with my symptoms of pain in my leg and was told go straight to A&E – waiting in beds – waited for ages –shown into small room, curtained off, seat for each patient.

Doctor come to see me. It appeared nothing to worry about. I was eventually discharged at 10:30pm. But nobody gave me the reassurance of what they'd found or why they had reason to not worry about my leg. Patients will naturally worry – and they have a lot of time to think about their symptoms – seems reasonable to provide reassurance where you can on discharge ?

Insensitivity of passing on bad news. Whilst I was there, I was aware of a Lady who was clearly desperately ill – she had been 2 nights without sleep before taken to Cramlington with breathing difficulties. There all night, sent home with antibiotics. Following evening was even worse, again there all night- in a bed. Heard her being given the news then she had tumour of the lung. Dreadfully difficult trying not to listen or invade someone's privacy? she was distraught.

Initially my experience and the gaps in compassion made me swear that however ill I wouldn't return to Cramlington. Of course I have been back twice since !!!

I nearly didn't share this with you because recently my daughter had outstanding care on ward 6 – but I thought this issue needs highlighting – the conveying of bad news. – and how important it is that we do this well. Surely, however busy staff are - there must be better ,more human ways of having these conversations ?

I don't want to make a formal complaint – and I'd also want to say that the Staff in the oncology department are brilliant. Dr Atherton is so inspiring – but I would like this anonymous story to be told at Board. It would allow me to know that the most senior leaders of the Trust were paying attention to this important issue.