FACT SHEET Tips from the real world: a patient's story

A case from the real world: unrecognised deterioration

This story is told by Polly (not her real name), who nearly died in hospital after a series of failures to recognise or respond to her clinical deterioration. Polly is a wife and a mum. She is an experienced critical care nurse who, at the time she became unwell, was working in education and toward a post graduate research degree. Polly developed excruciating and debilitating pain, and woke one night thinking that she had developed a life-threatening illness.

I went to the emergency department (ED) at my local regional hospital where I had some investigations and was sent home. Over the next few days I had continued problems with severe pain and I developed further symptoms that were causing me great distress and concern. I went back to ED and more investigations were ordered and I was admitted to the medical ward.

When the consultant came to see me the next day he didn't introduce himself or acknowledge me at all. He came over to my husband, slapped him on the back and said 'don't worry mate, I'll get her home for the weekend so she can catch up on the washing.' I was furious; he knew nothing about me and was treating me like a stupid housewife. I also strongly disagreed with the diagnosis I was given and I did not want to be discharged. When I questioned the consultant, he said 'well it's lucky you're not the specialist' and walked out the door. I asked to speak to the registrar. After some robust discussion, eventually my care was transferred to a specialist at the local private hospital.

At the local private hospital, I was admitted to the medical ward and seen by the specialist within 24 hours. He ordered more tests. By this time the pain was getting worse again and I was being given pethidine and feeling very unwell.

For the next week I got sicker and sicker. I wasn't eating and was hardly drinking, and I struggled to perform my personal care. The specialist would come and see me every 2 days or so for about 30 seconds, increase my drugs and leave again. Nurses would write down my abnormal observations and not act upon them. While the ward did struggle with short staffing and a less than effective nursing skill mix, it seemed as though the nurses were hesitant to provide care to me, as another nurse. I wasn't being helped with personal cares very often and there were a number of shifts where I didn't see my nurse at all. I wondered how they had enough information to write a report on me. I'm usually really assertive, but as a patient I found it impossible to speak up.

So I was just taking the drugs and lying in the bed. My husband, friends and family were coming in and getting more and more concerned about how I was deteriorating. After about a week, another specialist came in to see me. All I remember is that he told me I wasn't trying hard enough to get better. I really started to doubt myself; I got up, dragged myself for a walk, nearly collapsed, came back and vomited everywhere.

In the second week, I started to have palpitations. The nurses took so long to respond to the bell, they would never catch them on the ECG, and the resident who kept getting called to see me dismissed the reports of my symptoms and decided that the problem was anxiety. I remember at one point saying, 'look, please can you just trust me and listen to me. I'm not suffering from anxiety!'

Two weeks into my hospital stay, two of my colleagues from work came to visit and were shocked at my condition. They could see just how sick I was and, after speaking with my husband, went to see the director of nursing to organise for me to be transferred to a tertiary hospital in the city. While this was happening, one of my colleagues washed me and cleaned my teeth - I hadn't been able to wash myself for days.

While my friends were there, my husband was wandering the hospital and ran into an intensivist, who we knew socially. My husband asked him to come and have a look at me. He came straight away, took one look and immediately organised for me to be transferred up to high dependency while we were waiting for a bed in the city hospital.

I still don't really know what happened. I suspect it was dehydration and electrolyte imbalance and drug toxicity but I don't know. When I arrived in high dependency the high dependency staff pressed the arrest buzzer because the resident who thought I was suffering from 'anxiety' wouldn't come. I was so hypertensive I could feel my blood pressure beating in the tip of my nose. I lost consciousness, developed tetany, and became apnoeic.

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

recognising + responding TO CLINICAL DETERIORATION

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I remember when they started bag-mask resuscitating me, I was lying there thinking 'is this it, is the last memory my kids are going to have of me going to be me shouting at them this morning when they bumped my bed?'

I remember the intensivist leaning over me as I was waking up and him saying 'it's alright, it's under control now, and I'm going to take care of you'. It was such a relief. I was being observed, and listened to, and taken care of. After two weeks in hospital I felt like this was the first time someone was looking after me. I felt like up till then I'd been in hospital on my own.

This experience was devastating because many of the doctors and nurses at the hospital didn't believe me and they didn't take care of me. It has taken me a long time to be able to think about this time in my life without getting upset, and to get past the anger that I had towards the hospital.

I worry that this could happen to me when I am a health professional who is educated, articulate, has lots of contacts and is surrounded by people who know what to do in that situation. This was a system I know, and people whose roles I understand, and they failed to care for me. What happens to poor old Joe Blow who knows little about health, has little understanding of his own body, and just gets what he's given? I feel so worried about people like that. I hope that by telling my story someone can learn something from what I experienced.

My top tips

- Listen to the patient, don't dismiss them – I know how busy everybody is, but take the time to really sit and listen for real. It's so rare these days to find nurses willing to communicate on more than just a procedural level. Two nurses stand out in my memory because of their willingness to take the time to sit and listen to me. It was so important for me to have someone willing to do that and it just didn't happen enough.
- Introduce yourself properly and avoid saying 'I'm really busy' – this was common amongst both doctors and nurses and it made me feel devalued and unimportant. As a patient you don't want to hold people up or waste their time and 'I'm really busy' makes you feel like you're not a priority, it shuts down conversation and any sharing of information.
- As a patient you lie in bed and you can hear the nurses who are 'too busy' at the nurses' station gossiping about their relationships, or talking about how 'hammered' they got at the weekend while they make your bed. It's so unprofessional! The lack of professionalism that I witnessed made me question whether I even wanted to be a nurse anymore. If you're with a patient, use that time to find out about the patient.
- Take care to do vital sign observations properly – I saw a number of nurses who had poor technique and appeared not to understand the significance of their findings. There is no point doing observations if you're not going to act on them – I know that's really basic but so many times it's just not done.
- Don't label people as being anxious! It seems that if you don't have a diagnosis then it must be a mental illness – in my case this was certainly not true and the 'migrainous housewife' label I was given was both hurtful and unhelpful.
- You have got to communicate with family. Somebody needs to be with the patient when the doctor is there – a nurse or family member who can advocate, ask questions and seek clarification. Nobody really talked to my husband in the first two weeks I was in hospital. I often couldn't remember what was said, and I was so unwell I couldn't communicate my needs effectively.
- Don't make assumptions about what your patient is like – act on evidence not assumptions. If you want to know about your patient, ask your patient.

Further information

Further information about implementing recognition and response systems can be found in the Australian Commission on Safety and Quality in Health Care publication *A Guide to Implementation of the National Consensus Statement: Essential Elements for Recognising and Responding to Clinical Deterioration* (2012). This can be downloaded from:

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