Consumer stories

When some people with a mental illness attend a general hospital for reasons other than their psychiatric problems, they sometimes feel that they are treated differently, or that the help they get is not very useful. While not all experiences are negative, these are some of the stories we have been told.

Story 1

Mine was a planned admission to have a hysterectomy. I went to the pre-op clinic and spoke with them about the concerns I had with regards to my mental health. I suffer from depression and anxiety and was on antidepressants that would need to be maintained while I was in hospital. I was particularly concerned about the effect of the hysterectomy on my depression.

I also told them I was very anxious about undergoing a major operation because my father had died on the operating table. Because of my anxiety attacks, I requested a pre-med so I would feel calmer before the procedure. It was agreed that my antidepressant medication would be maintained throughout my hospital stay and that I would be given a pre-med before the operation.

So many things went wrong — the whole experience was horrendous. I arrived early on the morning of the procedure, and had followed the directions of nil by mouth — which meant that I had been unable to take medication that day. I waited for ages for my pre-med and asked the nurse about it a second time. I was told that it hadn’t been charted and by then it was too late so they couldn’t give it to me. This did not help my feelings of increasing distress. I then had to walk to theatre and was escorted by a very tall man — but he walked quickly and I had to run to keep up with him. By the time I got to theatre, I was quite distressed and really needed some reassurance that my care plan would be followed.

When I came out of the anaesthetic I was very unwell, vomiting and haemorrhaging which couldn’t be stopped. I was moved to intensive care and spent four days there, still haemorrhaging. I was on a morphine drip, and was a mess. My wound became badly infected. I wasn’t eating. I hadn’t been given any mental health medication as it was thought that I was self medicating.

Five days after my operation, I was pacing the ward at two and three in the morning. I yelled at my husband and kids just because his shorts were dirty. I’d yelled at mum on the phone and was acting irrationally. I became suicidal. I felt so unwell. It felt like no one seemed to notice (or care) that I was upset.

I rang my husband and asked him to come and get me. I tried to keep calm, thinking that he’d come soon. But he didn’t turn up for what seemed like a
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long time and I figured he wasn’t coming — so I left the ward because I didn’t feel I could handle it any more. Luckily, my husband turned up and stopped me and took me back to the ward.

I told the staff I wanted to be discharged. I left the hospital, staples still in, still haemorrhaging. When I got home, I became delusional. My husband called a doctor who immediately sent me to emergency at a different hospital. Because of my blood loss I needed a blood transfusion but was unable to have this because of the infection. The staples were removed and the whole wound opened up. I was too unwell to go to theatre for it to be cleaned and restitched. I stayed for another four or five days until they got it cleaned up a bit. I came home with a wound about 20cm-wide and a hole in my stomach that was still bleeding. I still have a very nasty scar.

Some of the things that would have helped:

✦ Ensuring that it was noted that I had a mental health issue. My mental health as well as my physical health needed care while I was in hospital — and I was too sick to advocate for either.

✦ Ensuring the care plan was documented and followed — from pre-op through to recovery.

✦ Checking in with me to see how I was feeling — especially in the context of my mental health problems and the meaning of having a hysterectomy. I really needed someone to ask me ‘are you okay?’ and to help me identify what supports I could call on.

✦ Intervention when I was showing obvious signs of distress (for example, pacing the floor and screaming at my family) and help to de-escalate my distress.

Story 2

I went to the hospital with severe pain in the right side of my stomach and I told the nurses that it was very painful and I could hardly stand up. I needed someone to look at me. They asked me some questions and then wanted to know when I was last at James Fletcher Hospital. I said I didn’t think that was important as I was in severe pain. They asked more questions about my mental illness and I kept saying I was in a lot of pain. The nurses seemed to think that my mental illness was far more important. Eventually, I was seen by a doctor who actually was interested in the amount of pain that I was in, not the fact that I had a mental illness. It turned out I had a cyst on my ovary.

Story 3

On a day two years ago at about 3pm, I began to experience symptoms that were quite foreign to me — trembling pain, pins and needles in my arms and hands, chest pains, severe stomach cramps and breathing difficulties. I thought I was going to die. I was lucky that a friend called over in time and she paged my psychiatrist for me. I was so weak and out of breath that I couldn’t speak to him. He told my friend to take me to the hospital just to be on the safe side. (I had recently stopped taking an antidepressant because it had given me dangerously high blood pressure).

We arrived at the hospital at about 5pm. The nurse got the run down on why I was there. I had an ECG three hours later. Then I had to wait for a doctor to see me and tell me the results. At 9pm the doctor came in. By this time, I was exhausted and emotional and very confused. I didn’t understand what had happened to me. Until that afternoon I thought my life and my health was just starting to pick up. I asked the doctor to explain what he thought was wrong. He said, ‘Your ECG was normal, you’ve most likely had an anxiety attack.’ I was shocked. I asked him if these attacks would be a recurring thing or if I’d be right from them on. He replied ‘If it happens again just lie down in a dark room.’ Then he just left.
Story 4

A consumer was admitted to the hospital recently. She was having hallucinations and did not trust the staff with her medications. The consumer called me (the consumer project officer) to go to the hospital to try to ease some of her thoughts and ideas. When I got there the staff said to me: ‘She’s from James Fletcher Hospital, what do you expect from her?’ I said to the staff that regardless of where the patient has been before, she needs to be shown respect. The main problem occurred when it came time for the medication. The consumer refused to take it from the nurse unless she had been shown that it had come out of the correct box. The nurse said ‘Don’t be stupid, just take it.’ I suggested that it wouldn’t take long to show the consumer that the tablets had come out of the different boxes. The nurse finally agreed to do it but I don’t think she was very happy.

Story 5

I was referred by an orthopaedic surgeon for a procedure on my big toe that involved a cortisone injection to treat osteoarthritis. I had undergone this procedure once before so had some idea what to expect. I have Bipolar disorder and was recently diagnosed with an anxiety disorder as well. I was quite anxious and can become quite obsessed with health problems.

There was the doctor and two staff who were observing (I think they were students). I was able to see the placement of the needle on a monitor. One of the students was being very reassuring and taking her cue from the doctor and informing me what was happening. The doctor was very focused and not answering my questions. To me it looked like the injection was going into the bone. I could also see some bleeding. When I mentioned this he denied it which made me more anxious. He would just say 'I'm a senior doctor and it's fine.' The student however was being very reassuring, using a measured tone of voice and acknowledging my anxiety. At the end of the procedure the doctor said it was very successful but then my toe went stiff. I had not experienced this before and the student was no longer present. Others were less patient with their reassurances and seemed not to value my need for information. It felt like they wanted to get it over with quickly.

It would have helped if the doctor had acknowledged when questions were asked and explained that things were proceeding as expected. I had to wait half an hour or so after the procedure and during this time the student reappeared and showed interest and concern and offered me a cup of tea and a sandwich. She also asked me if there were any other questions. The student validated my concerns and made me feel looked after. I think if she had not been there I would have been much more anxious. I would have felt alone and that no one was listening.