

The narratives

Introducing the narratives

The narratives used in this learning resource are intended to illustrate some aspects of five people's lives. These will explore various issues pertaining to people who happen to have learning disability and recount their experiences with health care professionals. Each of the units will invite you to reflect on at least one of the narratives.

You are asked to read the narratives of Marie, Shona, Scott, Alan and Purdie. Consider each of these and then reflect on how you have responded to people with learning disability in your clinical setting. Talk to some of your colleagues and find out how they have responded to people with learning disability.

Marie

I'm in supported housing now and I'm getting the right treatment. Recently I was asked by my GP to participate in the training of nurses to highlight the problems that people with disability can encounter. I am looking forward to this as it should prove beneficial to all concerned.

Story 1

When I was 10 years old, I was taking 30 tablets a day for epilepsy. I was told that I would not live to see my 16th birthday. I am now approaching my 41st birthday and my medication is down to 12 tablets a day. I have not suffered an epileptic seizure for six years. When I was told of my life expectancy, I was living in a children's home and I was told by Doctors in my general hospital.

When I was on 30 tablets that was before all the modern medication came into force. Purdie can tell you what seizures I was having. She would know - the two of us went to the same centre.

Story 2

The only problem I have encountered with the NHS is when my epilepsy was questioned by a student Doctor. I felt the Doctor thought I was faking my condition. However, a senior Doctor put the student straight and reassured me and told me not to worry. I felt if the student had checked my medical history, this need not have happened.

I was having an EEG at the time and she didn't even ask my medical history. My file was as thick as the Guinness Book of Records! She discharged me but I only got as far as Casualty and then I had a fit. The consultant gave her a row!

That should never have happened at all - it's terrible. That time when I was taken back into casualty, it happened in front of an ambulance. Casualty phoned the Neurology Department and the consultant came in and saw me and ended up getting the police involved and she was sacked on the spot.

Shona

I am a woman in my late thirties who works for a self-advocacy organisation.

Story 3

My first story is about Practice Nurses giving out wrong information and getting people really confused.

I use sharp pins for testing my blood sugar level. I said one time when I was at the hospital, what do I do with these? They said, if you take them to the doctors, they will get rid of them for you. But the Practice Nurse said, "I will do it this time but not again".

So the hospital was saying one thing and the Practice Nurse something else. I was really confused. I live in a flat and I don't just want to put the sharps in the bin where children might find them.

I phoned the Practice Nurse and the hospital. All you need is a thing to take away the sharp edges of the pin. They don't make it easy!

Story 4

Nurses are scared of us - why?

I spent two months in hospital 5 years ago and I felt very lonely because I picked up a bug in hospital probably. I was treated no different.

Why don't nurses see me as a person not as someone with a condition?

There are some things I want to say.

I think there is a lack of information.

It is not good if people have to wait a long time for an appointment.

What happens if you are an emergency? Are you left to attend this appointment on your own?

Scott

Story 5

My name is Scott. I live by myself in a ground floor flat. I work a number of days a week in a garden job. My community learning disability nurse comes to visit me from time to time.

When I was 10 years old I had an eardrum operation on Christmas Eve. I was ten and a half weeks in hospital. I had thick bandages around my ears and nurses came and looked. When I asked questions they just walked away. It made me feel like I wasn't being treated like others. There was some 2nd year and some 3rd year nurses. It was better when there were Sisters. Sisters told you a lot more and took a lot more time to talk to you.

They made me feel like I wasn't there when they kept ignoring me. I wanted to know as much as possible. This was the longest time I'd ever been in hospital. On Christmas Day the nurses wore tinsel and made it feel more Christmassy.

I can still remember the way I felt.

Story 6

After mother passed away I collapsed on the way to the shops and my ulcers burst. Next thing I remember after my operation I was in a lift. I don't like lifts! I told them but there was nothing they could do. A nurse was waiting at the other end. The lift broke down. The nurse shouted at me for being so long. I wasn't sure what was happening. I was not expected. I felt that even if nurse was tired she shouldn't have shouted. The next thing I remember I was in bed. I told them about what I remembered about coming round. Nurse didn't give me a lot of information. They don't seem to give you enough information - they seem to give you less if your have a learning disability. Maybe they think you won't understand. They tell the person in the bed next to you, but they don't tell you.

It doesn't make you feel great when they are taking blood 3 or 4 times a day. I wanted to know why they were doing it. I was in hospital for five and a half weeks. They didn't give me any food. They didn't tell me why not. I was hungry.

Only twice I had a visitor. One was from the Church. There were one or two nice nurses. If they noticed you didn't have a visitor they would spend half an hour with you chatting. It was nice and it passed some time. I was feeling a bit depressed after mother had died. I couldn't go into her room without hearing her voice. I was grieving without knowing it. The nurses didn't talk about it. I don't think they knew what to say. I wrote how I felt on my computer.

The information I was given wasn't what I wanted. They wouldn't tell me why they were taking blood. They refused to tell me. I felt they could have told me. I had a sore arm after some weeks. I had injections for the pain after the operation - every 4 hours. The stitches burst and I was asked if I'd lifted anything heavy. I had to go back into hospital for 6 days. There were some good experiences. The nurses who spent some time with you chatting and giving information - there wasn't many of them! The Doctor gave me a tour of the hospital.

Nurses should give people more information. They should show you what the ward is like. You should be shown what the Nurses and Doctors are like 2/3 weeks before going. You should be told what will happen. Their attitudes need to change. They should give everyone with a learning disability the same information as others. They should treat them the same as everyone else. They should take more time with people. They should tell people when medication changes. Doctors and Nurses have different ways of changing medication and telling you about this.

I don't always know how they feel.

Alan

Alan spent many years in a long-stay hospital. He moved to accommodation with support and is now in temporary accommodation with a voluntary organisation while he waits to return to his refurbished accommodation.

Story 7

When I was younger I saw two nurses, a male and female, threatening other patients by shouting and bullying them. I reported this, yet nothing was done about it.

I saw an incident where a guy couldn't get out of bed and the nurses were being very rough with him. They were threatening him saying they would hurt him if he didn't get out of bed.

Story 8

I went to see my GP by myself. I tried to explain how I was feeling and he told me to get out, he just would not listen to me. I was really upset about this.

Story 9

When my Dad died I felt really alone with no one understanding my feelings. I felt I needed more support from my family and others.

My mother was also sick at the time and I was worried I would lose her as well. I never told the staff at the hospital how I felt because apart from a couple of them I never felt like they gave me any help, understanding or support.

Purdie

I share a flat. I train doctors and nurses about health issues for people with learning disability. I think it is important to say about the good things that are happening.

Story 10

I made an appointment myself at the minor ailments clinic. I knew this was the place I would be seen by a Doctor and Nurse who would look into my problem, which was not serious. I already knew about the clinic. It lets my GP see more serious problems. The medical ailments clinic is a way of making the health service better.

Although I was not going to see my usual Doctor, who I think is good; I knew that the Doctor I would see would have read my notes. My GP is very good about putting down my information in the notes.

When I went to the minor ailments clinic I was first seen by a nurse. The clinic sees two people at the same time and the Doctor was in a different room when I saw the Nurse. I gave the Nurse information about my sore leg. I am lucky as I am able to say how many times I injured my leg. When I was 18 and also 21 I slipped on black ice. I fell again coming out of a shop when I was 32 and again two years ago.

When the Doctor came in he was able to talk to me and read the notes the Nurse had taken. I said there was something else wrong apart from my leg. The Doctor told me that the clinic only dealt with one thing. He examined my leg and told me I had damaged my cartilage and it may mean surgery. I said I had a karate competition and he said I better not compete this time.

I was surprised when the Doctor told me the problem was my cartilage. I was stunned when I heard what the Doctor said. 'Oh no, not more surgery.' I have had a lot of hospital appointments because I also have a condition called neurofibromatosis.

The Nurse had the right attitude. She greeted me in a friendly way. 'How are you? I haven't seen you for a while.'

At the clinic I found out what was wrong with my leg. However, I was not able to talk about my other problem. I was told that if my leg problem continued, the clinic would make an appointment for me to see an orthopaedic doctor. I don't think the Doctor or Nurse picked up my worries about more surgery.

I made the appointment myself. I only take a support worker when I go to the geneticist. The tenants where I live are not treated any different from anyone else. We are treated with the same respect as everyone else.

Callum's stories

We recommend that these stories are used in group discussions that should be facilitated.

My son is now 39 years old. He is a gentle giant, very caring, with a wonderful personality. People like him. He is like every other young man - he takes a great deal of joy in winding his mum up - in fact in winding anybody up! He enjoys using adapted bikes, wheelchair ice-skating, motorbike rallies, bowling, music, pubs ... just one of the guys.

He has profound learning disability and does not speak, although he can communicate in other ways if you know him. He also has severe epilepsy, and a long history of drop attacks and absences. When Callum was first diagnosed, he could take between 80 - 100 drop attacks each day, falling to the floor heavily each time. Until he took epilepsy when he was 18, he had good mobility. Since then his drop attacks and the medication given to treat them have created major mobility problems.

Story 1: Callum's epilepsy

Callum has a history of brittle bones, due to the use of Phenytoin to control his seizures, which has this side-effect. It also causes swollen gums. Despite his history of falling during drop attacks, nobody thought to tell us about these side-effects until he had been on the drug for two years. Over those two years, the number of broken bones he had was unbelievable.

We were given this information by a young junior doctor after he had been admitted to hospital with a broken ankle. By then he had already had a fracture in the arch of the foot, one in his collarbone, another of the elbow and five fractures in his ankles. He had also broken his thumb in two separate places, which was so bad it had to be pinned. On another occasion, he fell twice in a toilet, hitting his face on a grab rail and breaking his nose.

Although Callum seems to accept pain as part of his life can you imagine what all those fractures felt like?

At the next neurology appointment, we talked to the doctor about this, who then agreed to take him off Phenytoin.

Nevertheless, his bones remained brittle after he stopped taking Phenytoin and he was still taking drop attacks. During one of these, he had seven fractures in his lower leg in total, five at the front and two at the side.

He was taken to Accident and Emergency in the small hours of the night and was moved to A & E at another hospital because there was no radiologist available in the first to take the photographs. We were virtually accused of causing the damage ourselves. Callum was not offered any pain relief until the following morning at 7 a.m. This was finally given so that he would

'comply' with having a plaster put on. Only at 8.30 am, was he finally admitted to a ward and given a bed.

When we visited later in the day, Callum was sitting in a chair beside his bed with his leg on a footstool. He was grey. We asked if he had been given any pain relief. The answer was 'No - he didn't ask.'

This was after we had told all staff in detail about Callum's lack of communication.

I complained about this verbally and in writing but have never had any answer. In my letter I suggested that there should be a member of staff in the health team with at least *some* knowledge of learning disability. This was twenty years ago.

Since then he has also broken the metatarsals in his toes four times.

On another occasion, I overheard a nurse saying, 'I don't mind them when they're small, but I can't stand them when they are adults. They scare me.' Callum was listening.

Over the years because of a poor dental service and the side effects of all the medication he has had to take, Callum has now lost all his teeth. This has changed his smile but not his sense of humour. Apart from the Phenytoin, which affected his gums, many of the other medications including lactulose, fibrogel, ampicillin and other antibiotic syrups, have sugar in them.

After his first seizure at 18 he chipped the corner of a front tooth, and because of poor understanding between the dentist and Callum, he had to have a general anaesthetic. Callum had a hospital admission to have the tooth repaired and arrived back from surgery minus his smile - having had four front teeth taken out. I was devastated. I was so upset that when I went back to my car, I couldn't reverse the car. A man had to offer to do it for me.

Before Callum went to theatre, two junior doctors, an anaesthetist and a senior doctor had tried three times to persuade me to sign a form to consent to Callum having all his teeth out. I refused. One doctor said: 'I don't know why you are worried - he'll never be marriage fodder.' I was also told I was 'a very bad mother to put my son's life in danger, because didn't I realise that he could die if he had to have a GA for more dental treatment.' That was really intimidation.

Story 2: Deterioration in Callum's health

Four years ago Callum moved out of the family home and into his own house, shared with three other men. They receive twenty-four hour support. This move has not been without its own problems. There have been difficulties with the GP practice. Over the last year his healthcare needs were not properly monitored. Callum was depressed and after seeing his GP and a psychiatrist there was a possibility he was clinically depressed. He also kept having recurrent urinary infections.

In August the GP made a major prescribing error, which led to a massive overdose of a highly toxic drug. The drug Topirimate was supposed to be increased by 25 mg *weekly*, but this increase was written up as *daily*. Over a period of 7 days they took him up to 200 mg daily. This was on top of his other 4 anti-convulsant drugs. Apparently you are not supposed to have more than 3 at any one time, because of drug interactions. Callum was in a highly drugged state, his head down, like a huge heavy weight. He couldn't focus, drifting in and out of sleep, never conscious for any length of time. He seemed like a junkie might look. Because he was so drugged, he wasn't mobile as he had been before with assistance.

The error was picked up by his neurologist after a week, but the dosage could only be reduced gradually because of the risk of much worse seizures if taken down too quickly,

There was a possibility that the overdose could damage his liver and kidneys, but it didn't. However, from the August he was going downhill, culminating in November being admitted to an acute hospital. He was still on a big dose of Topirimate. His symptoms were high temperature, not eating or drinking, drifting in and out of consciousness. Meningitis wasn't being ruled out. The consultant diagnosed a chronic infection, very high up the urinary tract.

Because Callum was mostly unconscious, the staff only saw a young man who in their eyes was very disabled, not a person with a great personality and a very enjoyable lifestyle. We had to point out to them the individual he was.

He was admitted on Friday. On the Saturday, I queried his medication. I knew they had made another mistake in his medication. He was getting what was on his chart, but had been written up for half his correct dose. They didn't discover that until the following Thursday, despite my telling them of my concern.

The ward had no hoist or sling. Visiting family and carers had to wash Callum and change his clothing.

The infection did clear up but that Thursday evening, the consultant took us to one side and informed us that he couldn't see Callum getting any better, and what did we want to do? I asked if Callum were in a vegetative state and he replied 'No', but he didn't think he would get any better than he was. He

again repeated the question, 'What do you want me to do?' He didn't explain what this question meant, even when I asked him to.

The following morning we arrived at the hospital to be told that Callum was being transferred to another hospital. Nobody explained why. The consultant took us aside and explained the reason why he asked his question. He said that when one of his patients reaches the end of their life, their relatives normally just want them to 'be made comfortable'. I wondered if I would have been treated the same.

Later that morning Callum was transferred to a big teaching hospital. The first day was just a maze of doctors and nurses, coming and going and asking the same questions. I was exhausted and it was all very traumatic. Over the weekend, Callum was fighting for his life. On the Monday afternoon, a houseman took me to a side ward and explained there was no hope for Callum - he was going to die. He asked me what I wanted done if it got to the stage where he would need to be resuscitated. He also said that he didn't think that Callum 'qualified' for an intensive care bed. Any treatment would only be given on the ward. I said to him that Callum was far too young to die and we wanted the same quality of support for him that we would expect to receive ourselves.

In the early hours of the following morning, the phone rang. The registrar rang to inform us that Callum was being moved to a side ward. We went straight away and arrived at the hospital to be met by the registrar - a very cold young woman. She proceeded to tell us that Callum's quality of life was not worth fighting for. When we argued the point, she produced her senior - a neurologist. He agreed with her and added, 'After all Callum has uncontrollable epilepsy.' I phoned for extra support from family and friends with influence. We argued with the doctor who then brought in the consultant from ITU. Again Callum's quality of life was questioned and the value of giving him life-support. The registrar said that if we wanted him to have life-support, there was no way he would get it in that hospital. Only when our friends arrived to back us up, was the decision made to support our son. One-to-one specialist nursing support was provided, with the option of ITU if needed.

Gradually we got the staff on the ward to realise that our son was a real person. He then got excellent support. But why did we have to go through hell to get this for him?

Although there were still problems for him, the support was there and he began to improve. Attitudes changed and the staff were delighted when he responded to treatment.

Callum is back in his own home. He is still not 100%, but progressing daily and enjoying his life again. His mobility however has been badly affected by his treatment over the past year and he still cannot stand unsupported. We don't know whether he will walk independently again. We hope he will.

Issues for consideration with Callum's stories

When your facilitator has given you directions on how to use this last narrative, you may care to consider the following issues in relation to the recommendations of 'Promoting health, supporting inclusion (2002)':

The person

- Respect the person - see the individual, not the disability.
- Imagine how he or she might feel: what would it have been like for Callum during his hospital admissions?
- Communication - communicate at the individual's level.
- Pain - just because it isn't readily apparent and the person cannot clearly express it, does not mean it is not there.
- Respect the person's dignity.
- Equality of care and right to treatment regardless of disability.

The family

- Recognise the expertise of the family - and listen to them
- Think about the acute stress on families when a relative with learning disabilities is ill.
- Consider the practical load on family carers. Can you help with that?
- The family not only has the anxiety about their son or daughter's illness but also, at this particularly difficult time, has the extra responsibility for teaching staff about his/her needs and acting as advocate. What does this mean for the family? How can you help?