

Being prepared for hospital visits

My mother always used to tell me to wear clean underwear in case I had to go to the hospital in an emergency - she said don't be caught in holey undies! Well I listened to my mother on this one and the other day when I fell off my pushbike I landed in hospital with holes right through good underwear and ruined my best pair... so much for her good advice! But a friend of mine, ended up in hospital unconscious after a fall off her bike. The doctors gave her some antibiotics while she was knocked out but did not know she was allergic to it; she got a very bad reaction and nearly died. The doctors did not know of her allergy and she was not able to tell them because she was knocked out. Because the patient was not able to talk, she nearly got much sicker.

Most problems in the hospital occur due to mix ups in talking and listening - and we want to try to prevent these from happening by being prepared for any hospital visit. The message is to be prepared if you have to go to hospital. Sometimes you might need to visit the hospital for a regular appointment with the physiotherapist or physician or dentist, or sometimes it might be unexpected, say, after a fit or a nasty fall.

Some of the medical people may not know much about Down syndrome and the physical health problems. Some people with Down syndrome do not use words to speak and the medical staff may not understand sign language. And some people with Down syndrome need to talk about what the doctor says afterwards to understand and decide what to do.

Sometimes, in hospital you might be so unwell that you just cannot speak. Other times, doctors may suggest an operation and ask you to sign a consent form - it would be a good idea to discuss this first with your family or friends. The doctors and nurses at the hospital need to know about you as well as your health problems.

Tips for a successful visit to the doctor

1. A first important point for you visiting the doctor is to be accompanied by a regular carer whether that be family or paid worker or both. This person's role is to assist you in communication and help tell your story in an accurate manner, if you need assistance. It should be someone you know well and trust.

Many adults with intellectual disability are unable to report physical health symptoms using words. Health professionals may not be skilled at recognising the types of facial expressions, vocalizations that might indicate that the patient with intellectual disability is not well. However, family members or regular support workers or caregivers may well know how to recognise when their client 'is not themselves'. Inaccurate information or gaps may lead to unnecessary illness due to delay in diagnosis and treatment.

2. Know who you are seeing and why and when and where

This should be discussed with the patient with intellectual disability in an appropriate manner, their caregiver, or support friend or family member too.

If it is an appointment with a specialist, a referral letter will be required. Prepare for the appointment before hand with by discussion between the patient and their entire support team. Get there in plenty of time in case there are stairs and lifts or difficult to find (as is usually the case in hospitals).

3. Take along:
 - Photo of you when you are well - this helps Drs and nurses know you
 - Have a bit of a list that outlines your skills and the things you might need some help with - this helps the doctors too
 - Medical notes regarding reason for this appointment
 - Medications (Webster pack if you have one)
 - Referral letter if to specialist
 - Medicare card
 - Medical file from home or old medical notes
 - Relevant charts eg seizure recording chart, bowel chart, weight, prefilled questionnaire
 - Background information about you which may be left with the doctor
 - Names, phone numbers and addresses of your statutory Health Attorney, Next of Kin, Case manager.

4. Be prepared for questions you may be asked by the doctor
 - What is the reason for this visit?
 - What are the symptoms that have occurred recently?
 - Has the person's behaviour changed recently?
 - How is their appetite, bowels, energy, sleep?
 - Please describe the events you think are seizures...
 - What was the earlier development of this person like?
 - Is there a family history of illness?
 - What are the usual medications? Allergies?
 - What are the usual skills of the patient?

Prepare in house meeting before appointment.

5. Prepare questions that you may like to ask

Don't be afraid to ask questions

What are the medications?

Are there any side effects?

What is the diagnosis?

What is the treatment?

What do we have to watch out for?

What do we do in an emergency?

When do we see you again?

If you would like an example of the papers to take to hospital to help the doctors please write me a letter to the address below and I can send you on a sample of how to prepare for a visit to the hospital.

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SHAID clinic for adults with Down syndrome is held the second Thursday of every month at the Mater Hospital.