Lynn, Don and Alex's story about getting better health care.

Alex starting having seizures at 7 days of age and we were in and out of Camperdown Children's Hospital (in those days) and then Westmead Children's Hospital for years.

We wanted to say how important and how difficult it is to be forceful and I guess demanding in the hospital setting. For instance, when Alex was only a couple of months old and was once again in Emergency (at Nepean Hospital this time) they had found it very hard to find a vein for a canula. This in itself is so distressing to watch, especially when Alex was so young, vulnerable, helpless and we were so stressed, emotional, beside ourselves with worry etc. At one point one of the young doctors said that another young doctor would "have a go" as he'd never had the opportunity of putting in a canula in such a young baby. At that point Don just said "NO, definitely not. You're not practicing on our baby". We know it is a teaching hospital and people have to learn their skills but not in this circumstance. This would be a difficult for many parents to say but you just have to be forceful and not let the system override your wishes. In the end they could not find a vein and put the canula into a little vein in his head. I'll never forget it!

Another example would be when Alex would be admitted as a young baby/child, the hospital staff would just expect us to leave. Don would have to say "we're not leaving, you'll have to find me a chair or fold away because I'm staying with Alex". They would. Circumstances may well have changed now. Certainly, as a man, on his admissions over the past couple of decades, they have been more than happy to have one of us stay with him.

> It is also imperative to find a GP who is relatable and empathetic. We are fortunate to have a terrific GP who knows Al and is happy to spend time and actually likes to interact with him.

Al is not anxious about going to the doctor because the surgery knows him, welcomes him and it is not a terrifying and traumatic experience for him. He even had his flu shot easily last year. Consistency is so important too. It is very difficult to relate to a GP who is new and who you might not see again.

One of the most difficult things for us with regards to Alex has been dental care. Alex will not sit in a dentist's chair and willingly and happily open his mouth for an inspection. He must be sedated/anaesthetised for any examination. When he was younger we took him to a paediatric dentist who every few years would, at a day hospital in Westmead, put him under a general anaesthetic and do whatever work had to be done. This has been so much harder for us as Alex is now a big man!

A few years ago he had to have some dental work done and we managed to arrange for him to see the anaesthetist and the dentist and they agreed to do the work in the Day Hospital at Lithgow Hospital. Unfortunately this did not work out well as Alex aspirated into his lungs during the procedure and had to spend a week in hospital with IV antibiotics for aspiration pneumonia and then home with antibiotics and ongoing care for a while. He has not been to the dentist since and we know it is overdue. We are just not sure what to do and who to see as Alex was understandably traumatised by this event (and so were we!)

Of course, it has always been difficult for Alex to have x-rays, ultrasounds, blood tests, tests of any sort really. It is difficult for some doctors or health professionals to understand just how difficult it is! We were given a request for an orbital xray of Alex's teeth once. He was expected to stand still on a stand while a machine tracked around his head taking x-rays of his head/mouth. Nope. After many exhausting efforts we gave up. Again, you have to be strong and just say "No, we are done". You'll have to think of another way around this. He has to be anaesthetised for ultrasounds, MRIs etc. It just becomes so hard. Blood tests are a nightmare. You hope and pray that the technician is empathetic and capable!!

It is difficult too because obviously Alex cannot verbalise just how he is feeling or the symptoms that he might be experiencing. For example, a lot of people experience oesophageal reflux and are quickly sorted with an simple medication. Alex wouldnt be able to verbalise that sensation of burning in his chest so might just put up with it, sometimes having a funny look on his face that I always wonder about. Could it be reflux?? Just an example.

It's that not quite knowing what is going on with his body/health that is a worry. He can say my back hurts (and he does have severe scoliosis) but we tend to sympathise, give him a Panadol and hope it will go away because the investigations will be so difficult. His gym/physio sessions are helping him and we haven't had to look further down the track over the past 20 years.

We are blessed in many ways with our Al as he is personable, likeable and adaptable. He takes oral medication with no problems at all and to a limited degree understands that doctors, nurses and technicians are there to help him.

Don and Alex are a father and son smiling together.

Who is it for?

People with intellectual disability,
Family and carers,
Professionals

What is it about?

Ways to get better health care,
How professionals, family and carers can respect health rights,
Communication

Who made it?

Lynn, Don and Alex

When was it made?

It was shared here 3 weeks ago.

This story was made by

Lynn, Don and Alex

Lynn, Don and Alex are members of the Our Health Space community from NSW.