



Office of the
Public Advocate

reinforce
self advocacy
OWNERSHIP OF OUR OWN LIVES

The right of people to make their own medical decisions

October 2019

Real stories inside





Message from the Public Advocate and Reinforce

Everyone has the right to play an active role in making decisions about their own health and to receive the support they need to do so.

Reinforce is a self-advocacy organisation run for, and by, people with an intellectual disability. The Office of the Public Advocate is an independent statutory body that safeguards the rights and interests of people with disability in Victoria. Together they have produced this brochure to promote the role of supported decision-making and importance of communication in medical decision-making.

The law says people can make their own medical treatment decisions, providing they have decision-making capacity to do so. That is, if they can understand, retain and weigh up relevant information to make a decision, and can communicate it in some way.

A person could have decision-making capacity if they were given support.

Examples of support include:

- taking additional time
- using modified language or visual aids, such as pictures or video
- someone who helps by discussing information or assisting to communicate a decision.

This brochure includes stories from three people with disability — a powerful reminder of how every individual should be at the centre of decisions about their own health.

Colleen Pearce

Colleen Pearce, Public Advocate

Colin Hiscoe

Colin Hiscoe, President, Reinforce

Kim's Story

Before I had my brain injury, I didn't have a problem dealing with medical people. If I didn't like what they were saying or I didn't like what they were telling me, or the treatment they were giving me, I felt that I had the choice to do something about it.

After my injury, for at least two years, I had no control over anything. I didn't know what to say, and I felt that quite often I wasn't listened to.

I always make sure I take my support person to appointments when I can in order to make any sense of what they're saying; he translates for me and does it very well. He'll summarise for me and ask the questions again.

Some of the medical professionals will talk to my carer and not me. And it's actually about me. If my carer needs to back me up and clarify something that's fine, but it's so rude to direct their questions at them. You lose confidence in your ability, at a time when you should be actually building up your abilities.

'Patchy' would be the word to describe the experience. You have some really good people and then some people who really have no clue, no idea how to deal with people with disabilities.

Often a medical person will pose a question and I say 'Can you tell me a bit more about that?' and they just say the same thing. They have no idea how to rephrase the question or break it down.

If I could do anything about the relationship with the medical profession it would be giving them some help with answering questions in a way that makes sense.

The stories here are true but names of the three individuals have been changed to respect their privacy.

Cover artwork by Anthony Romagnano
3 ladies, 2014, pencil on paper, 38.5 x 56 cm
 © Copyright the artist, Represented by Arts Project Australia, Melbourne.
 Arts Project promotes the work of artists with intellectual disability.

Lee's Story

A lot of disabilities are hidden. Intellectual disability is a hidden disability.

It should be one of the topics they talk about, so new doctors and nurses are trained up on disability from the very start. They should use guest speakers with lived experience of disability like self advocates.

When they check you in at the hospital, one of the questions should be 'Do you have a disability?' and, if yes, they can give you a different coloured wrist band so the doctors and nurse know straightaway that you've got a disability and can take appropriate steps and not use jargon. And, say, if have to handover to another doctor. All the information should be there and highlighted.

I haven't had any bad experiences, except for them not asking me about my disability and using too much jargon. I've got a good story of when I went to see a doctor at the hospital for my sleep apnea. At that time, I had an outreach worker with me, just in case I couldn't understand anything. The doctor got rid of all the jargon words and explained it down to the last thing, the outcome of my test and everything, so I understood. He broke it down and made it easy for me to understand and he spoke to me, not my outreach worker, which was good.

In my opinion, hospitals should talk to patients, not the carers or parents. If the patient can understand, they should talk to them. Just because we have a disability, we should still be able to make decisions on our own behalf.

"Good medical practice involves... providing information to patients in a way that they can understand before asking for consent."

Good Medical Practice: A Code Of Conduct For Doctors In Australia,
Medical Board of Australia

A way to check: Can the person explain the information back to you?

Mei's Story

In the past, when I saw the doctor, he was too impatient. When I told him about my fits, he would always say "I'll put you on extra tablets" but sometimes when I was on too many tablets, it made me sleepy, I had double vision and was tired all the time. Even when I told him that, he wouldn't do a thing about it. I put up with it for so long.

When I moved to Melbourne and started going to another doctor, he took his time and got to know me really well. Sometimes I would ask "What does that word mean?" And he would have patience to explain it to me... and when I was still having the fits, he would make sure I was on the right medication.

After I had surgery, that's when things started to change for me. That's when I started to be more independent; going to the doctor on my own and explaining to the doctor about my problems. My health got a lot better, and I started to feel free as a bird. And that's the way it's going to be for the rest of my life.

Now they listen to me when I go to the doctor, and they even look directly at me. They take their time with me as well. I have my caseworker with me, but they look at me and talk to me, not her.

They've still got a lot of work to do in terms of speaking to the patient, and speaking in plain English, not jargon... and even to the ones who can't speak (non-verbal), to put pictures there!

We need to teach people and the doctors, or people who want to be doctors, what our situation was like so they don't go there again.

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More information

Medical Board of Australia

For the *Good medical practice: a code of conduct for doctors in Australia*

medicalboard.gov.au

Office of the Public Advocate

Information about medical decision-making laws

Phone: 1300 309 337

publicadvocate.vic.gov.au

Reinforce Self Advocacy

Information about the work and history of Reinforce

reinforce.org.au

Voices Together

Online resources for self advocacy groups, government and community, including videos and fact sheets

voicestogether.com.au

Centre for Developmental Disability Health, Monash Health

Education, training and resources for health practitioners

cddh.monashhealth.org

Council for Intellectual Disability

Communication resources, including 'My health matters' folder and video

cid.org.au/issues/health

Oral health and intellectual disability: A guide for dental practitioners

Guide and video available on the Designlab, major projects, section of the Inclusion Melbourne website

inclusionmelbourne.org.au