

Editorial: Building better lives - the role of formal support

In the 16th century the Polish astronomer Nicolaus Copernicus put forward a radical theory. He argued that, despite what people thought they were seeing, the planets were orbiting the sun rather than the earth and that the earth was just another planet. For the past thirteen hundred years everyone had 'known' that the earth was the centre of the universe and that the sun, moon and stars had all revolved around it. His declaration challenged the foundations of how people saw the world and their place in it.

Working to ensure that people with disability and families take their place at the centre of our universe, with the service delivery systems revolving around them, may be a modern day equivalent of the Copernican revolution. This paradigm shift requires us all to let go of long held beliefs and practices that had service systems firmly established at the centre and people and their families in orbit around them. Transitioning to the NDIS has the potential to be a revolutionary and fundamental change in how we think about support and a sizeable shift will be required from us all to achieve it, no matter where we fit in the universe.

In this edition of CRUCIAL Times, you will find illustrations and discussion on what support can look like when it is being offered well. At the heart of the messages in this edition is the notion of working one person at a time; to listen to and discern what each person really wants and needs and then to work with the person to assist them to achieve this. Our five writers, a number of whom require daily support due to disability, all speak of the need for reliability, respect and dignity and support tailored to what they need. This daily support is a means to an end not an end in itself. This is not very different to what any citizen expects when they engage a professional formally for expertise or support.

As the number of people directing and managing their support increases, it is not surprising that people report when support is targeted to their needs it increases their satisfaction and motivation as well as the efficiency and effectiveness of the support. Research also indicates that staff employed in such systems are more satisfied and generally stay longer.

It is not complicated, however we have a long history of thinking that because people with disabilities need some things to be different or special, we respond to all of their everyday human needs with things that are different or special. This thinking gets in the road of supporters listening to the person and appreciating the power of the typical response for all of us.

As things change and people with disability and families have more choice and control we would be naive to think that all power imbalances will suddenly be realigned. Paradigm shifts like this take time and thoughtful analysis and a willingness to change from all parties.

Former Canadian activist, Judith Snow points out that when formal supporters understand the person's goals and aspirations, as well as their needs, they play an invaluable role in assisting the person to take their place in their community. When the foundations of support are well provided then people can get on with life; go to school, university, and work or go out with friends. In her article

Sharon Bourke discusses the needs of the person with disability being central but not at the cost of respect for and valuing of the worker and their role. Sharon talks about the importance of collaboration and shares many practical points from her experience of assisting her son to manage his own supports.

Working "with" people and using common sense, honesty and good ethics is critical for both parties. If power is to be shared appropriately both parties also need to be reliable, trustworthy and reasonable in their requests and understanding of the consequences of their directions. This will help in establishing a culture of mutual respect which is a vital element of working together for a shared purpose.

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Reinventing Emma - Excerpts.

Emma Gee

Emma Gee is a public speaker, author and consultant who lives in Melbourne. Her work draws on her experiences as both an Occupational Therapist and a stroke survivor. Through her reflections on being an allied health professional and a patient she is well placed to discuss the realities and challenges of person-centred support. For more information please visit her website: emma-gee.com

The following is a selection of excerpts from her autobiography "Reinventing Emma". These excerpts commence after Emma is recovering in hospital following surgery for an arteriovenous malformation (AVM). The AVM caused a stroke and there were complications from her surgery.

Reinventing Emma

As I became more awake and aware of my surroundings I found my life depended on and was dominated by hospital staff. In my former life nurses and other health professionals were just part of the team, but now as a patient my relationship with them was quite different. I was helpless, a child, so reliant on their good grace to get through each day. And, as in all cases, there were wonderful staff members and those who were not so kind. Some, without realising it, made me feel quite humiliated in my new role.

In those first few weeks I was unable to look after my most basic personal needs, like washing my hair...

Although I was feeling so traumatised being in this new body, I felt forced by the hospital environment to keep up. For me each event I faced was enough to deal with in a lifetime, but to others it was just part of the daily hospital checklist of tasks. I didn't have time to recover from one activity before being thrown into the next. The staff seemed to think that if I was given time to contemplate the difficulty of what was happening, I would never move forward. [Page 101]

Some nurses made me feel like a person rather than a patient. Jacqui was my favourite. She would carry out each task cheerfully without complaint. Even when giving me a sponge bath, rather than leave me lying naked on the bed, she would only uncover the necessary parts, ensuring that I remained warm and maintained the tiny bit of dignity I still had. She made me feel special, whether opening my curtains for some sunshine, or reading my get-well cards. She listened to my muffled speech and grunts and patiently attempted to figure out what I was saying, and moisturised my dry feet.

At night Lee and Ruby continued the amazing care that Jacqui had shown. Lee was so gentle in her manner and wore her soft grey hair in a bun on the top of her head, reminding me of a fairy-godmother. In her presence I slept better, knowing I was in good hands.



Actually, most of the night nurses were amazing. Knowing they were awake and watching me was so reassuring. I never would've endured that initial phase of my recovery without the generous care I received. My writings capture very humiliating and demeaning situations that prevailed in my diary and mind. I tell these stories to highlight the enormous impact another's words or actions can have on one's recovery. Being aware of those tiny things, often overlooked, can make all the difference. [page 107].

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As her recovery progresses, Emma moves from hospital to a rehabilitation centre. In the following excerpts she is adjusting, not only to this new environment, but also to the reality that she now requires support.

Although I had improved I was still having trouble keeping up with the rehabilitation centre. It was a fast-moving, efficient place, because they wanted me to be independent, but sometimes their careless action and brisk attitude had the opposite effect.

Whether it be forgetting to shut the bathroom door and revealing my naked body to the world, asking me if I'd like a Malteser when I couldn't eat chocolate or swallow properly, failing to put the bed brakes on, or giving me a 'wedgie' while holding the back of my pants when walking me, there were numerous incidents during my stay that reinforced my feelings of dependency and powerlessness. I'm sure these actions were not intentional, but in my AVM victim mentality I saw them as such. Already feeling vulnerable and defeated, I became fairly cynical about the treatment I was receiving and that cynicism certainly didn't help speed my recovery.

In rehab I needed help with just about everything, but hated asking for it. Some people seemed to make the whole process rather difficult. At times the staff seemed too busy to attend to my needs or would frequently avoid eye contact to save time. [Page 127]

This excerpt begins as Emma has moved in to her own home, following a short period of living with her parents after leaving the rehabilitation centre.

The chance to be independent was so exciting, but as I looked around my new, empty home I felt overwhelmed and alone. Everything is trapped in big boxes that I rely on others to empty. I know where I want things put but can't move to put them there. It was the beginning of a dark and growing feeling of dependent independence that I still lug around today. [Page 176]

The elation I had felt when I moved into my new home had proved to be short-lived. My newfound independence was replaced with a feeling of helplessness, reliance and doubt. I never envisaged that well over a year after my stroke, I'd still be so heavily dependent on those around me. [Page 180]

In the chapter "Dependent Independence" Emma describes the challenges of re-establishing her life in the community, in particular finding a balance between accepting the support she needs, and maintaining the independence that is central to her identity and sense of self.

To be eligible for any service from community organisations, though, I had to highlight in each assessment what I could no longer do - something I preferred not to think about too much. After a number of depressing assessments I was allocated a regular carer from the council for a couple of hours a week.

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I could achieve a lot more in my day.*

The decision to let a random stranger invade my personal space was not easy. I confess that at first I was defensive, and critical of everything they did. Sometimes they'd begin tasks assuming what needed to be done. "Let's let some light in here and brighten this place up. It will cheer ya up," they might say, pulling up the shutters that I had deliberately left down to lessen the glare that hurt my now ultra-sensitive eyes. Some helped themselves to a choccy or two from an open box, flipped through a book on my bedside table or told me to do things in a different way. While I felt happy to offer them a chocolate or adopt their suggestions, the forceful way they seemed to take over my own home made me feel bitter and resentful. Watching someone else do things that I once could do for myself just rubbed in the reality of my own helplessness.

It was even tougher when they did things their way, without considering the outcome. One carer made my bed, tucking the white sheets in firmly under the mattress. She failed to realise that I didn't have the strength or the control to untuck the sheets. That night when I tried to 'post' my body between the tight sheets, I kned myself in the face, resulting in a blood nose.

Now I'm able to admit that the presence of home carers in my life has been invaluable and I am so grateful for their assistance. But initially it was a frustrating time for me. [Page 176]

I was adamant about still having some control over my new home. I refused to listen to therapists' recommendations that I purchase an electric scooter to replace the rusty manual silver car that I no longer could drive, or modify my bathroom and install rails around my new home. In my state of denial I continued to stubbornly believe that

putting in ugly disabled equipment was a waste of money and unnecessary when I was on my way to a 100 per cent recovery. Accepting any modifications to my home symbolised permanency and disability confinement, and suppressed any chance of hope. Those around me would assume I was no longer improving. I don't think my therapists understood my state of mind and often took my refusals personally. Of course their suggestions were right and in fact did seed the ideas.

In 2011, six years after my stroke, my parents (and main caregivers) decided to move to the country... When they sold the family home, 10 minutes away from my unit, they also took a big chunk of my support with them. I realised how many little things they'd done for me. With my parents leaving, I had to delegate my support. I hated burdening others, particularly my siblings. For several months after my parents left, I tried to live pretending I didn't need anyone to help me. I stubbornly refused to accept or even ask for help, and didn't want to become reliant on strangers and feel the need to repay them for their support.

Jobs like putting out the rubbish and cleaning up dog poo I had gradually let my parents do without feeling too guilty. Now when friends came around to see me I had to ask them to do these tasks, eating into our catch-up time. It seemed to unbalance the relationship, them becoming more like carers in my eyes...

After accidentally locking my keys inside my unit three times in a row and flooding my laundry twice, I realised I couldn't rely on my parents' frequent but irregular visits to help me. I had to structure formal supports into my life. I told myself to snap out of it and began to notice the positives. Gratefulness and resentment can't co-exist...

I gave spare keys to friends, had a friend mind my dog Gilbert when I travelled, began shopping online, caught more cabs and increased my weekly council homecare hours. My siblings and close friends happily took on many of the tasks that my parents had previously done. All these changes empowered me to live independently and I'm sure my parents didn't feel as guilty. I saw that by asking for and accepting support, I could achieve a lot more in my day. I became reliant on my parents more for emotional support, through reassuring phone calls or chats over Melbourne coffees when they came to town.

In the chapter: 'Life Now' Emma shares the joy in her life and some of the plans she is making for her future, including getting back in to her passion of travel.

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or interpreting their kind offers as devaluing.
I'm probably now a better travel partner.*

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When travelling with friends I need to organise trips with smaller groups of people. As time has gone on they have become so mindful of my extra needs. Hiring cars, carrying my luggage, making my bed, booking accessible Accommodation or cooking my meals are just some of the things my friends now do that make holidays so much easier. Accepting their help is better than becoming frustrated or interpreting their kind offers as devaluing. I'm probably now a better travel partner.

As time goes on, the prospect of travelling and holidaying overseas with others has become less daunting. So many adventures, opportunities and possibilities are ahead of me.
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**Reinventing Emma
by Emma Gee**

(Openbook Creative, 2016)

**is available from the CRU bookstore
or from Emma's website:
www.emma-gee.com/-the-book**

**It is available in both paperback and
as an e-book.**