



Interview with Barbara Lewis

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Your career pathway to date

I have been very blessed in the places that I have worked in. I started off as a consular officer with the British embassy in Spain. It was at that point that I started counselling: when supporting people affected by car accidents or other incidents that brought them into the Embassy for assistance. Then I went off to the BBC world service where I was exposed to working with people who had left war torn countries. When I came back to Australia, I worked with the ABC in News and Current Affairs, and I think probably, in a nutshell, I would put my career pathway as very strong social policy – a belief that we support people in our community. As a result I have put myself through university and degrees that have led me to this point. I started with the Carer Support Service when it was being established by NSW Health back in 2004, and I have been chipping away ever since. I am blessed to walk beside carers everyday who have different journeys, a variety of things that make their journey complex; from parents of a child with an intellectual or physical disability through to husbands and wives who's partners have motor neuron disease or are frail aged or have dementia. It's a very varied role but what I like about it is I am able to inform good social policy in Northern Sydney Local Health District in terms of the recognition and engagement of carers as partners in care.

Tell us about the Carer Support Service

It is a state-wide service funded by the Ministry of Health and you will find us in all the Local Health Districts across NSW. Our role is to ensure that health services are able to 'think patients - think carer'. When we use the term 'carer' we are really establishing that that term is applied to a family member, partner, or friend. Carers are not support workers and are not employed in the role to provide care and support. We help with guidance and the best analogy is walking side by side. We are not there to take over a carers life or to fix all of the problems; but we certainly try and help facilitate what they need.

What are the main aspects of supporting carers?

Every carer would say something different, we work to

empower, care and connect carers in Northern Sydney. We like to think that we are empowering carers to have a voice, we show them care and consideration and we connect them to the information or services that they need to access. The biggest thing that anyone can do is listen, and appreciate that there are many views and many responses and many reactions to life experiences and there is no one easy answer. There are a variety of different journeys and different hurdles as no two people have the same issues.

What are your main projects?

One project is improving the hospitalisation of people with an intellectual disability, but it is also about improving the primary health components of care so they don't get to the point where they need to access hospital at the point of crisis. If, for example, a client/patient and their carer are connected to a Psychiatrist early enough with good health care and medication in place, it doesn't end up being a hospitalisation for an injury that was due to frustration and certain behaviours. Since the closure of the government disability provider ADHC, there has been a considerable extra pressure on carers as a result. Cross agency collaboration remains a key component for positive patient care, with sensible ways of communicating and facilitating care, as after all, all professionals want the best circle of support around an individual child and their family.

How has the NDIS improved caring for a child with IDD?

At this moment in time I haven't experienced many families that have said it has improved their ability to care for their child. It does appear that those who previously had no support are now receiving some funding. I do fear that many families are still struggling to put it all together.

What challenges does the NDIS bring for carers of a child with an IDD?

One challenge I am noting is that carers probably had access to services in the past that might have been cheaper but are now more expensive, sometimes

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there is not enough money in the plan to cover all the needs of the child. Accessing services and being very clear on what a carer wants for their family member is really important. I also note that sometimes carers are struggling to find the right service providers, and good support workers to provide care. It is also difficult for different businesses to bring the care together, eg. a behaviour support plan done by one business, relies on being able to train staff from other organisations, this is difficult to achieve.

Where can carers go for additional support?

There are some considerable changes that are going to be bought about by the Federal Government such as asset testing the carers allowance. In the past, carers were not asset tested which will have an impact on the health care card. There will be a lot of changes over the next year or so. I urge carers in Northern Sydney to keep an eye on our website

www.nscarersupport.com.au. If carers are stuck they can always contact our service for help. Alternatively, there is the *Carers Gateway* and Carers NSW as peak providers. On the ground there are Advocacy Services that will be there to assist.

Some fun Questions: Favourite book

I actually have two books. The first is by Mary Delahunty and is called *Public Life, Private Grief* and that is a fabulous book. Mary Delahunty was a member of

the Victorian government at the time that her husband passed away. So that was a lovely story about her family's journey. Then the other one that I love is *Tales from the Political Trenches* by Maxine McKew, which was written after she left Federal Government. Maxine was one of the key people within Kevin Rudd's team that was instrumental in social policy reforms, which sadly, at the moment we are seeing being discounted. It felt at the time that we were going to see really good social policy - and that was from the National Apology to the stolen generation through to the NDIS, which of course was from the government at the time.

A weblink that you would like to share

Beyondblue and Blackdog because they are both wonderful resources for people to quietly access in their own homes and be able to look at how they can manage their own levels of stress and anxiety. Or even if you are just feeling a little bit blue, there are a lot of self-managed care approaches rather than having to sit in a room with a clinician. And of course our Carers website, www.nscarersupport.com.au

One thing you always take on holidays

My pillow! My pillow has even travelled to Paris and wherever! Nothing like putting your head on your own pillow at the end of the day.

Is there is anything else that you would like to add?

I think that we really need to emphasise the importance of a community around carers and recognise, respect and value them as partners in care. That is across all sectors whether it is health, education or community support. The caring journey is tough, it doesn't matter what type of journey it is, it is a tough one. We need to really have that respect in place.

