



FACING DOWN MOTOR NEURONE DISEASE

For every person who dies from Motor Neurone Disease each day, another is diagnosed. At any given time 1300 people in Australia are living with the disease, **Felicita Benedikovics** discovers.

Images of the world's most famous astro-physicist, Stephen Hawking propelled Motor Neurone Disease into public awareness in a way few diseases have. Dependent on several full-time carers and an elaborate machine to verbalise the thoughts he hasn't been able to speak for nearly three decades, Hawking continues to produce remarkable work.

Every major disability requires massive adjustments and some families, like Hawking's, splinter from the stress.

Others fortunately, learn ways to minimise the impact and sustain equilibrium within the family.

Nicole Wallis (34) from Victoria was diagnosed with MND two years ago. Six months earlier she was showing her four-year-old daughter Lily, who had just started ballet lessons how to point her toe. When Nicole tried to point hers, she discovered she couldn't.

"I wasn't overly concerned as I had been getting lower back pain back and I was doing Pilates to help strengthen it,"



she says. It prompted her however, to see a neurologist to determine the cause of the problem.

Nicole was tested for a raft of illnesses and diseases including multiple sclerosis, until her doctors concluded she had MND. "It was the only disease left on the table," explains Nicole.

It wasn't the family's first exposure to MND. Nicole's father-in-law died of the disease when he was just 54. "For as long as Nicole had the symptoms we were desperate for them not to tell us it was MND," says her husband Shane, a finance director. "For the six or seven months we didn't have a diagnosis there was always the hope it could be something else. Already knowing about MND, kind of made it harder to come to terms with."

“I wasn't overly concerned as I had been getting lower back pain back and I was doing Pilates to help strengthen it.”

Brain Australia describes MND "as a group of disorders in which the nerve cells (neurons) that control muscles slowly degenerate and die". The estimated life span is between two and five years. Typically MND shows in one area first and slowly becomes generalised although its progression varies from person to person. There is no known cure and treatment options are limited.

"You don't go around thinking 'I've got MND,' I'm still me, but over time it does have traction." Now using a wheelchair, she found it difficult to let go of plans to study and become a teacher, but the mental and emotional cost is harder.

"I have bad days, when I can't stop crying, thinking 'Why me?' but the children keep me from wallowing. When they are around, I try to make a big effort not to be like that."

Shane says their children – Lily now six, and Bailey four – help keep things in perspective and allow them to focus on living for the day. "We make the most of the time we have," Shane says. "Before, you tended to let time go by, but now we make sure we have fun together."

Both draw strength from keeping things normal for their children. "Nicole wants to do all the things mums do," says Shane. "So we are working to keep her independence for as long as possible."

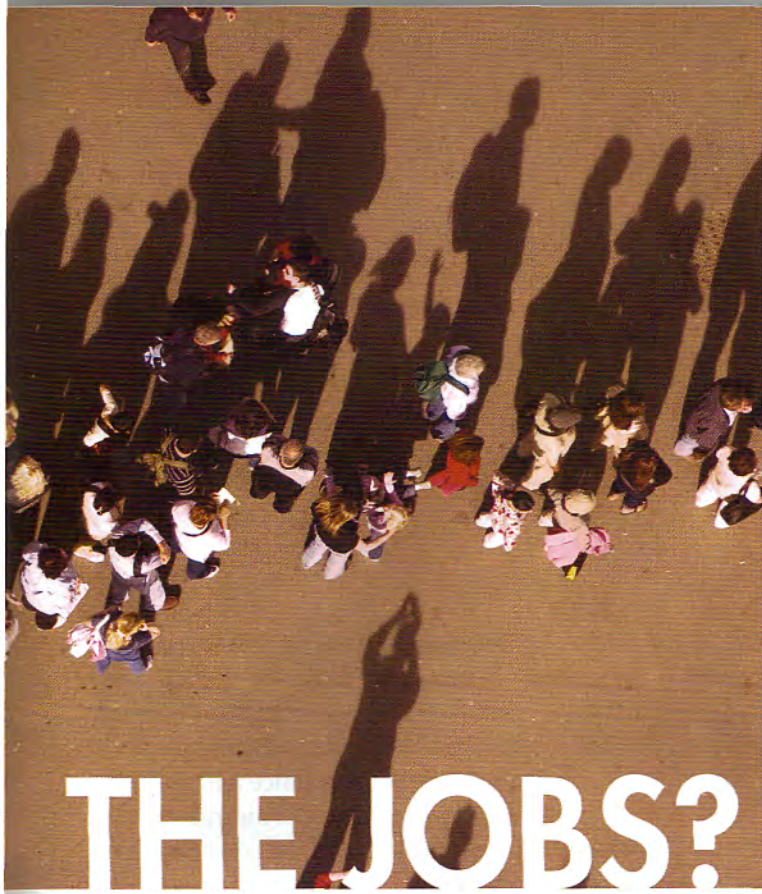
Often people recently diagnosed with MND flounder for information and support which is why the Motor Neuron Disease Association Australia is a real boon in linking people with services that can improve their quality of life.

Carol Birks, National Executive Director of MND Australia says people need a rapid response when they contact services for equipment to help them remain independent and get on with daily living. "A month makes a difference with MND," she says. "And while the disease will progress anyway, the idea is to live the best life you can for as long as possible."

As MND effects every aspect of life – speech, breathing, mobility, incontinence – a host of services need to be put in place, including palliative care to ensure patients and families receive the support and care they need when the end approaches.

"People with MND are often put on waiting lists," says Carol. "But this is simply not an option because by the time a person with MND gets to the top of the list there's a realistic chance they could have died."

■ continued page 29



THE JOBS?

Greater effort is needed to inform and work with employers to promote the capabilities of people with disabilities and dispel the many myths around people with disabilities in the workplace. The NMHDES acknowledges this.

Many employers, perhaps the majority, have no idea of the assistance available to them such as disability employment services, and workplace modifications. And a lot more information needs to be presented to employers who shy away from employing people with mental illness.

Changing the culture and expectations of employers and the community is what this promotional work should be about. Unfortunately cultural change takes time. Changes to the infrastructure are also necessary before we will see more people with disability taking active roles in the community; the Access to Premises Standard and Transport Standard won't come a minute too soon.

The changes and improvements in the supports available to people with disabilities looking for work are fantastic and people will use them. But bigger and harder changes, the ones that will provide jobs, involve our culture and infrastructure. As someone staring into the teeth of change famously puts it, "Yes we can!"

For more information on reforms to universal and disability employment services visit www.deewr.gov.au

For more information on the employment of people with disability go to www.jobaccess.gov.au.

FACING DOWN MOTOR NEURONE DISEASE

■ from page 21

For Nicole and Shane Wallis, focussing on the present helps to sustain them but they recognise the future will be hard and they want to make the transition as gentle as possible for all of them, especially the children.

"We talk about what's going to happen," says Nicole. "I want to have things in place for the future as much as possible. I bought a book yesterday called 'What is happening to me?' for Lily when she gets older and her body starts to change. That's when you really need your mum around and I won't be there."

Two years on from the diagnosis, Nicole says the disease is progressing slowly and, with luck, she'll be at home for some time yet but she knows their plans have to be flexible. "We both agree with the plan as it is now but you can't be too hard and fast about it. You don't know what it is going to be like at time.

"We have talks about not wanting to die in a hospice. I don't want to be ventilated; that kind of physical stuff we have decided together. But I have to be realistic. It might be a strain on the children for me to be at home. I don't want them to think of home as a hard place to be, so it might come to the point where I can't be here."

Fortunately, their home has not needed radical alterations to accommodate Nicole's wheelchair but Nicole admits they'll need to get more help at some point. However, she is reluctant to bring too many people into their home too quickly. "I want to be the major influence on the children for as long as I can," Nicole explains. "There are things I can't do but I can still turn them into good children. I'm not helpless."

Shane and Nicole say an individual and co-ordinated approach to the care they require now and in the future is crucial. But consistent quality care cannot be guaranteed says Carol Birks.

"Each association strives to provide referrals to quality care, but not all are able to. The availability of those services varies so much, some receive world class care but some don't."

Remaining light-hearted and anchoring their young children's security is an act of immense love and will that would defeat many people facing imminent loss. That can't be squandered by inadequate services when the Wallises will need them most.

The MND Association provides services in every state and territory.

Visit www.mndaust.asn.au for contact details or call the national freecall number: 1800 777 175

3 - 9 May is MND Week