

MOTOR NEURONE DISEASE



Family outing: Murray Ryburn, who died of motor neurone disease on October 10, with his children, Caitlin, left, Finlay and Megan.



Battler: Matthew Fraser has spent many hours fighting for the best equipment to help him deal with motor neurone disease.

Photo: David Hallett

Bureaucracy an extra battle

Mike Houlahan

Christchurch woman Liz Ryburn should receive some mail within the next few days answering requests for funding or support to help her family cope with her husband's motor neurone disease.

It is likely to be too little, and it will be too late. Murray Ryburn died last week, with many of his family's battles with the health bureaucracy to make his last months bearable still unresolved.

"I know bureaucratic wheels move slowly," Liz Ryburn said.

"I know that ministerial questions need lots of looking through notes and checking, but I will be very sorry Murray didn't hear the answers. I think an acknowledgement - 'Thank you for your letter, we will be looking into this' - wouldn't have been too much to ask."

The Ryburns and many other families confronted with the ravages of motor neurone disease (MND) - a fast-moving and ultimately fatal disability of the nervous system - have had to deal with a cruel catch-22. The sheer speed with which MND kills often outpaces the length of time it takes to process funding requests for essentials, such as wheelchair ramps or caregivers.

The Ministry of Health is trying to streamline the processes that can bog down home modifications.

"However, it is important that relevant building standards are met to ensure safety for people using the structure and the durability of the building," the national operations manager at the Health and Disability

National Services Directorate, Trish Davis, said. "This takes time."

Time is a luxury patients such as Murray Ryburn do not have, and their final days can be made more stressful by battles to maintain their dignity and way of life.

Liz Ryburn has many stories of her family's battles with health bureaucracy. For example, in March, her husband's occupational therapist decided he was eligible for a special chair designed for easy transfer between the seat and his powerchair. A standard chair was delivered but was found to be unsuitable. The family found an alternative, but approval to fund it was not confirmed until August.

"The expectation was that for five months he wouldn't have anywhere to sit," Ryburn said. "If he had had no money, he literally would have had nowhere to sit for five months... with a particularly vicious and rapidly changing disability that's not good enough. You do need fairly instant responses."

Davis said access to support services and funding was prioritised based on the urgency of a person's needs. Short-term solutions were available and could be utilised while longer-term solutions were arranged.

"Where a person is deteriorating rapidly, other solutions, such as equipment, additional personal care, household management, carer support and respite, may be offered," Davis said.

"The district health boards may offer supports via palliative care, such as community supports or hospice."

Matthew Fraser has one word of advice for people diagnosed with motor neurone disease.

"Noise."

Fraser can barely say the word - his speech is severely hampered by the fast-moving, debilitating disease that is shredding his nervous system and will eventually kill him. Instead, he nudges over his powerchair - a machine controlled by proximity sensors set up around his head - and slowly uses a mouse to type into the computer, which then speaks on his behalf.

"Noise," he says. "Noise. Noise."

Fraser, 38, was diagnosed with MND in March 2005. Since then, life has been two constant battles: one against the disease, and one with the bureaucracy of the health system to access benefits and services.

Fraser's set-up is so efficient because he has spent hours online finding the best equipment, and then many hours after that fighting to get it installed for his use. It is expensive, and taxpayer subsidies only cover a limited degree of the cost.

Also only partially subsidised were alterations to the Frasers' suddenly impractical two-storey house. A ramp and a rebuilt downstairs bathroom and bedroom were needed to accommodate Fraser but the available funding - which had not been adjusted upwards for many years - came nowhere near covering the cost.

Like many families dealing with MND, the Frasers have dug deeply into their savings to try to make life as easy as possible. They have welcomed help from family and friends, and even from unexpected sources like the builders who worked on their property.

"You can end up being hamstrung by the system," Fraser says.

"It eats up time you could better use for other things," his wife, Zara, adds. "But we're very lucky that Matt has always been very pro-active, and whatever he thinks he is going to need he is on the case before he needs it to push it. But if you get someone who is a little bit older or who isn't geared up with a computer... it would be hugely difficult."

The couple have three young children, Harriet, six, Damian, four, and Margot, three. They also have a large staff of caregivers, and the help of family and friends.

"It's like a train station," Zara Fraser says.

"There are a staff of 10 people coming and going constantly, and then you have occupational therapists and whoever else end up coming over so we do try and have quiet moments."

However, getting that level of support was difficult, and the Frasers say they often had to stamp their feet, in a nice way, to get what they needed. Many times they were left struggling without help, although things are much improved now they are on an individualised funding system which helps meet some of their needs.

Fraser says he is telling all the MND people he knows about the system. Again, it comes down to making a noise and doing the best to live your life.

"Own your disease and don't wait for the system," he says.

MND falls into a limbo within the health system. It is regarded as a disability, but not being caused by an injury it is not covered by ACC - a nicety which affects people with a wide range of disabilities. They are left to apply for funding, but in the case of a disability like MND, its progress can often outpace the system.

The Ryburns are all too familiar with that catch-22.

Motor neurone disease strikes down people with terrifying swiftness, often debilitating them or ending their lives before health services can act to help them. MIKE HOULAHAN speaks to two Christchurch families dealing with the disease.

Families stricken by deadly disease

■ "I know when I first wrote to you all that I said I didn't think life was only about trying to live well but also about trying to die well too. This seems like such a huge ask now. The thing I'm frightened of most is that my courage will fail me."

"In the long hours of the night I often lie in bed and inevitably think what my last weeks and months will be like when I cannot talk at all (as this is now becoming very difficult for me), when I can't move my body any more (by now I really only have a little hand movement in my right hand and movement in my right leg) and when I am struggling to breathe (which is starting to happen as my lung capacity has reduced to about one-quarter of what it used to be) though my mind will still be working."

"There will, I hope, be ways I can communicate with the aid of computer technology, but there will not be any real expressive language, any nuance, any humour and any precise shade of meaning. I fear that I will move into a twilight world, but I have so much to say and so little ability to actually express it." —Murray Ryburn, writing to his family, September 2, 2008

■ "After telling my parents the news and having a good cry that night I went about looking into as much research as I can find in working out is there a strategy to either fight or at least try to slow down the progression so I can spend as much time as I can with my family doing the things that a father should do."

"I am just a normal guy with a very normal family that due to our unusual circumstances is now on a very special journey." —Matthew Fraser

FACTS

What is motor neurone disease?

■ Also known as Lou Gehrig's Disease or ALS, MND is the name of a group of conditions in which the neurones in the brain and spine become weak and eventually waste away.

■ Symptoms may include twitching, cramps in muscles and general fatigue, tightness and spasms of the arms and legs. Eventually, the person will lose the function of their limbs and the muscles of the trunk and neck will waste away.

■ It is not contagious, and is seldom hereditary. About 200 to 250 New Zealanders have MND at any time. No-one knows what causes it.

WHAT IS THE LIFE EXPECTANCY?

■ The order in which symptoms occur and the rate of the disease spreads can vary enormously. Life expectancy can range between six months and 20 years. The average is between two and four years

ON THE WEB

- <http://www.matthewfrasermndcharitabletrust.co.nz> (Matthew Fraser's website).
- <http://www.mnda.org.nz/index.html> (NZ Motor Neurone Disease Association)



Left behind: Liz Ryburn, with children Megan, Finlay and Caitlin, are learning to live a different life after her husband, Murray, died of motor neurone disease. Photo: Martin Hunter

Murray Ryburn, 58, died last Friday, with applications for funding and support still grinding their way through the official machinery.

"We were so angry that a lot of our time and energy was having to go into these battles, just to get survival," Liz Ryburn, Murray's wife, says.

"Whereas we wanted to spend quality time. Banging out a letter to (funding provider) Enable or to (local MP) Ruth Dyson, it was cathartic, but we shouldn't have been doing that. It shouldn't have been happening."

The letter to Dyson was spurred by the family's attempts to find funding for a caregiving programme which would allow Ryburn to live at home. The family's proposed "survival package" required 85 hours a week, but they were shattered when they learned the maximum allowable was 62 hours a week.

The Ryburns had already had to cope with no funding for wheelchair-modifications to vehicles, a four-month wait for a working electric bed, a three-month wait for a suitable easy-access chair, a botched modification to the bathroom which left the toilet at the incorrect height, and received incorrect advice to install a lift for the wheelchair - machinery which had to be taken out and replaced with a ramp, which itself possibly failed to meet building codes.

"When you individually meet the people, the needs' assessors, they are very obliging and are there to help you," Liz Ryburn says.

"But then they go back to their office and they can't do it. The system just doesn't allow it. To give someone who wants to die in their own home a maximum of 62 hours, and that's at \$21 an hour, you can't get night care at that rate."

Murray Ryburn was an internationally known social work academic before ill-health cut short his career in 2003. Further illness ensued, and was followed in 2007 by a devastating diagnosis of MND.

Eldest daughter Meg moved home to help care for her father, and her brother and sister, Finlay, 12, and Caitlin, 10.

"At the beginning it wasn't too awful, but from February this year onwards, it was really fast," Meg Ryburn says.

A family trip home to England in July coincided with Murray Ryburn beginning to use a wheelchair, and by August he needed a powerchair.

"From there it just progressed so fast," his wife says. "In the last three or four weeks the lack of lung capacity meant it was such an effort to speak, so to get a sentence out was really hard... but even two days before he died he

wanted to go out every day.

"He'd go down the ramp in his powerchair, go off around the park with the dogs, he'd have coffee at the coffee bar, he would have friends around. He would do wheelies in his powerchair, and would be alive and out there. He was a free spirit, and he suddenly wasn't a free spirit any more. He couldn't do things any more, he had to ask. And it was so hard."

Murray Ryburn finished a letter to family and friends on October 1. Nine days later, 18 months after his diagnosis, he died peacefully.

The Ryburns' house no longer looks the same. All the medical equipment has been cleared out, the over-flowing supply of medicines taken away.

However, there is a large ramp outside the front door, and a huge hole at the heart of the family that remains to be dealt with.

ST MARGARET'S COLLEGE
PRIMARY, MIDDLE & SENIOR SCHOOL

Primary School Open Evening
October 23, 5.30 - 7.00pm

We offer an education that embraces academic growth, develops skills in both sport and the arts, and a holistic approach that ensures the spiritual and emotional wellbeing of your daughter. Places are available in our year 3 - 6 primary school classes in 2009.

For further information please contact the Registrar:
Telephone 03 353 2563.

12 Winchester St | Merivale | Christchurch
Phone 03 379 2000 | www.stmargarets.school.nz