

Polio survivors may be left out of NDIS

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The NDIS will provide support and services for hundreds of thousands of Australians who need help, but many polio survivors will likely be left out.

The federal government’s new national disability insurance scheme (NDIS) will provide support and services for hundreds of thousands of Australians who need help, but it’s unlikely many polio survivors will be among them.

George Laszuk caught polio in 1951, five years before a vaccine became widely available in Australia. He was just 11 months old and ill with pneumonia at the time.

“I went into a hospital and unfortunately, the ward that I was placed in, one child had polio and gave it to the lot of us,” he says.

He was too young to recall the initial treatment, which included being strapped to a flat board *“for about a year”*, but he remembers the callipers and crutches that became part of his life.

Polio, a disease caused by a virus, affects the nervous system. One in 200 infections leads to irreversible paralysis which in some cases can be fatal.

Mr Laszuk recovered from the virus, but his back and leg were permanently affected. The callipers and crutches remained in place even as he worked, married and had a family.

“I was a fairly healthy person”, he says today, from the electric wheelchair he now needs to use to get around.

“One of the jobs I did, I had to go up two flights of stairs every day just to get to work. I mean, that’s how drastic it has gotten in 15 years.”

Late Effects of Polio

Like many survivors, Mr Laszuk worked hard to overcome his physical limitations during childhood. Doctors now believe he may have been better off preserving his muscle strength, because of what has become known as the “late effects” of polio.

Dr Stephen de Graaff, who works with polio survivors, says there are a range of problems that patients can face many years after recovering from the initial disease.

That could include more rapid wear and tear of muscles and limbs, but in more extreme cases the repercussions could be much worse.

“There is one group of patients where we see a more aggressive process occur, and this is what we call neurological failure”, he says.

“Some of the nerves that survived after the initial polio attack start to die off and this is at a quicker rate than what we see in normal neurological drop-off as we age.”

Fatigue and memory problems can also be an issue.

"We are now faced with a group of individuals who may not be sick, but they are physically challenged", says Dr de Graaff.

For George Laszuk, those physical challenges are severe. Curvatures in his spine and nerve damage in his leg make it impossible for him to stand for more than a few minutes at a time.

"I can just stand enough time to transfer from my chair to the bed, to the bathroom", he says. "And that's just the way it is, and there isn't anything anyone can do about that, except maybe [by providing] better equipment."

Too Old to Benefit from the NDIS

The federal government's new national disability insurance scheme will provide support and services for hundreds of thousands of Australians who need help, but it's unlikely George Laszuk will be among them. At 63, he'll be too old to benefit by the time the scheme is fully rolled out in 2018.

Minister for Disability Reform, Jenny Macklin, says the scheme's 65-year age limit is intended to prevent duplication between that system and the aged care system.

"The Government accepted the Productivity Commission's recommendation that there should be an age-65 threshold for entry to the scheme, on the basis that people should get the care they need in the aged care and the disability care systems and that there should not be duplication between the two" she told SBS in a statement via email.

"After receiving feedback from stakeholders, we have ensured that people with degenerative conditions who would benefit from early intervention supports can enter before age 65, and can remain in the scheme after turning 65."

"DisabilityCare Australia will complement the aged care system to ensure we are delivering a cohesive system that gives people with disability, older people, their families and carers the support they need."

Polio Australia president Dr John Tierney says the aged care system *"clearly isn't adequate"* to properly support polio survivors.

"We've got people over 65, and they can't find those services now. We will get second-rate treatment simply because we're over 65, and that's age discrimination", he says.

"When the scheme comes in, in 2018, we're on the 65th anniversary of the Salk vaccine. So all of us will be over 65, and we'll all be left out of the NDIS. Just at the time when we really need those services."

President of Polio NSW, Gillian Thomas, believes the government should consider a sunset clause in the legislation for polio survivors.

"They really only need to look after us for another 20 or so years", she says.

"Once we get to our 80s and 90s and are no longer on this planet, we're not going to be a problem."

Counting the Costs

Polio survivor Merle Thompson can walk without assistance only if she's going a short distance. Otherwise, she uses a range of walking aids to help her stay mobile.

Each pair of specially-made shoes costs in excess of \$1200, and that's just the beginning.

"I have to have either special shoes or callipers to be up very long. When I'm on slippery floors, I need to use a walking frame so I can balance on two hands, when I'm on the street I use a walking stick, and when I'm going long distance I use a disability scooter", she says.

"My car looks like a disability shop."

Fellow survivor Nola Buck is now in her 70s. She finds it hard to believe how much her body has deteriorated as a result of the late effects of polio.

"When you think of what we did as young adults, you know, I went overseas for three years and worked over there, hitch-hiked around England and ... had four children", she says.

Like Merle, she walks with the use of callipers but requires mobility aids to go long distances.

"I also use a wheelchair when I go into Sydney, and I have two scooters, one for rougher areas and one for footpaths and shopping centres. All of which I fund myself."

George Laszuk received funding for his wheelchair through government-funded disability support services. But other facilities, such as installing a ramp to enter his home, he paid for himself.

"[The NDIS] would mean a lot, as far as care goes", he says.

"There's equipment I desperately need, to help me transfer from the chair to the bathroom. I need equipment to get myself into the bath."

For Gillian Thomas, the federal government's decision to put an age limit on the NDIS is another cruel twist of fate.

"Younger polio survivors in the community will be covered by the NDIS", she says. *"So unfortunately I got polio just a little bit too soon."*