

ABC NEWS

Young people 'rot away' in aged care, three years after NDIS launched

By national social affairs reporter Norman Hermant and the Specialist Reporting Team's Loretta Florance

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PHOTO: Sarah Brady now lives at home, where she is assisted by carers and family. (ABC News: Loretta Florance)

Sarah Brady was a 39-year-old woman who could walk, talk and eat solid food when she was put into a nursing home to share a room with someone in their 90s who could no longer communicate.

Sarah lives with leukodystrophy, a neurodegenerative disease that affects mobility and speech.

After several serious falls at home in 2016, her parents said they were told an aged care residence would be the safest place for Sarah.

Almost immediately, they realised the move was a mistake.

"It's just not a place for the younger people," her mother Lyn Brady said.

"Because there was no-one around to really talk to her, she lost her speech."

She was also put into continence diapers every day, not taken to the toilet, and was constantly kept in a wheelchair.

"The ability of her walking and going to the toilet, that's completely gone," her long-time carer Fiona Matthews said.

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Key points

- In the most recent financial year, 2,578 people under 65 were admitted into aged care
- The most common way for young people to leave an aged care facility is by dying
- About 1 per cent of those people with an NDIS plan have disability accommodation funding



PHOTO: Lyn Brady brought her daughter Sarah home as soon as she got an NDIS plan. (ABC News: Loretta Florance)

Most weeks, she was confronted with another death, her family said, as her fellow residents inevitably reached the end of their lives.

"Unfortunately, she was around people who were [much] older than her," Ms Matthews said.

"She just kept looking at the old people and they weren't talking to her, because they couldn't ... she probably felt very segregated and unwanted and unloved while she was there."

Alarmed by what they were seeing, Sarah's family applied for the NDIS as soon as it rolled out in their area in 2017.

A year later, they had a plan in place and moved their daughter home.

That move made her one of a lucky few young people who returned home after spending time in an aged care facility.

Most common way to leave is to die

In terms of aged care, the Government considers anyone under 65 to be a "young person".

Official statistics reveal three years after the NDIS's launch, the number of young people with a disability being admitted to aged care residences has barely budged.

In 2016, 2,663 young people with a disability were admitted to nursing homes. In 2018, the number admitted was 2,578.

Most of those admitted were in their 50s and 60s. But hundreds were in their 30s and 40s.

The NDIS was partly designed to get people out of aged care and into their own homes or living with family.

The Australian Institute of Health and Welfare provided figures to Senate estimates that showed in 2017-18, more than half of people under the age of 65 living in nursing homes "separated from" — or left — the residences by dying.

Figures from the Young People in Nursing Homes National Alliance (YPINHNA) tell a similar story:

How young people left nursing homes in 2017/18:

Death	1,048
Residential care	391
Return to family or home	198
Other	136
Hospital	80

EMBED: Graph: How young people leave aged care homes

Bronwyn Morkham, from the YPINHNA, said any attempts to address the issue had failed.

"We've had too many years talking about this problem," she said.

"There have been many government attempts [to solve it]. But nothing has succeeded."

Living in dementia ward, without dementia

In Canberra, 58-year-old Angelina Giorgio is in a room in a locked dementia ward in an aged care residence, where she has lived for nearly three years.

Most days, she's left in bed all day, with only her television for company. She's rarely taken out of her room and she doesn't interact with other residents.

But Angelina does not have dementia.



PHOTO: Angelina Giorgio has spent much of her adult life in care. (ABC News: Elena de Bruijne)

"She's catatonic schizophrenic, and she's disabled, so being in here is really difficult for her," her sister-in-law Tania Giorgio said.

Angelina has spent much of her adult life living in care. After a suspected stroke in 2012, her family was told the only option for her accommodation was a nursing home.

At first, she lived in the home's "high-care" section, with residents who were at least two decades older than her. In 2016, the nursing home said because of her outbursts and yelling, Angelina would have to move.

She was transferred into the secure dementia unit.

"Because we had nowhere else to take her, we basically just signed her over into the dementia ward. And it's been the worst mistake we ever made," Tania said.

Angelina's ability to move on her own is now nearly entirely gone. On many visits, she barely speaks.

"Now, because of 24-7 in a locked room, she has no idea of what to talk about, what to say, how to speak to people," Tania said.



PHOTO: Tania Giorgio (left) is fighting to get her sister-in-law Angelina Giorgio out of a nursing home in Canberra. (ABC News: Elena de Bruijne)

Why is it so hard to leave?

Using a freedom of information request, Ms Morkham's organisation obtained statistics from the agency that runs the NDIS that revealed why it is so hard for young people with disabilities to leave nursing homes.

The figures show as of the end of last year, less than 1 per cent of young people in nursing homes who were also part of the NDIS, had Specialist Disability Accommodation (SDA) in their plans.

That's 32 people.

SDA funding provides money for independent accommodation, ranging from \$10,000 for home modifications to more than \$80,000 for a newly built accessible apartment.

Without SDA funding, it is often impossible to pay for the changes people with a disability need.

The Government has admitted there is a problem.

"I acknowledge there is a long-standing history of undersupply of suitable [SDA] in Australia," Minister for the NDIS Stuart Robert said in a statement.

Providing new disability accommodation funding for young people in nursing homes would take time, he added. But he said the situation was improving.

"The number with SDA funding in their plans has more than doubled [to 66] since December 2018," he said.

New figures reveal the number of young people in nursing homes with NDIS plans also increased from 3,626 to 4,721.

The Government said a new action plan would ensure those under the age of 45 living in aged care would find appropriate housing by 2022, and those under the age of 65 found appropriate housing by 2025.

Ms Morkham said while the plan was welcomed, there was still no indication about how it would actually be carried out.

"We've yet to see an implementation strategy," she said.

For young people in nursing homes with NDIS plans, there is no indication of how the plan will boost personal care in aged care residences where staff often don't have the training or the time to care for people with disabilities.

"There's still no clear vision for how that will happen through the action plan," Ms Morkham said.

'I'll keep fighting'

After years of lobbying by her sister-in-law, Angelina is one of the lucky young people in nursing homes to have crucial SDA added to her NDIS plan.



PHOTO: Angelina Giorgio spends most of her day in bed at the aged care facility. (ABC News: Elena de Bruijne)

The money will pay for Angelina to have a place in a new group home scheduled to open in Canberra later this year.

"It's been a long battle," Tania said.

"I'm not suggesting Ange is going to suddenly come back and go 'everything's right'. But at least having 50 per cent better care is better than she's getting at the moment."

Once her sister-in-law is out of the nursing home, Tania said she would keep working to get the same result for others.

"It's just so wrong on every level that we allow these people to come in here, younger people, and just rot away in a bed," she said.

"I'll keep fighting. To get people out of nursing homes."

Topics: health, older-people, community-and-society, youth, aged-care, mental-health, disabilities, carers, vic, mill-park-3082, melbourne-3000, australia, canberra-2600, act, griffith-2603