



‘People have forgotten about polio, they’ve forgotten that we’re still here, dealing with the after effects,’ says Gayle Kennedy. Photograph: Carly Earl/The Guardian

## Australia’s polio survivors: ‘They’ve forgotten that we’re still here’

For most, our previous pandemic is a distant memory. But for these five polio survivors new health problems have just begun

by **Sophie Black**

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**A**ustralia was officially declared polio-free in 2000. Two decades later, for many people the only time they’ve stopped to think about the disease was the moment the poliovirus vaccine certification was stamped into their medical

records, or later, their children's. But for many polio survivors in this country, and there are approximately 40,000 of them, the last 18 months have served as a reminder of living with the last virus to **shut down public places** and spread fear through communities.

Of the several polio epidemics that occurred in Australia, the most notable ones occurred in the late 1930s and early 1950s. About four million Australians were infected (although many cases went underreported), with about 20,000 to 40,000 developing paralytic polio between 1930 and 1988.



Photographs of Nola Buck as a child, the one on the far right was taken before she caught polio. Photograph: Carly Earl/The Guardian

Polio (poliomyelitis) is a disease that mainly affects children under five years of age. The highly infectious virus attacks the motor neurons that relay messages from the spinal cord to muscles, often leading to muscular degeneration. One in 200 infections leads to irreversible paralysis. Among those paralysed, 5% to 10% die when their breathing muscles become immobilised.

Like Covid-19, **vaccination** is the only effective preventive measure against polio. Australia began mass vaccination against polio in 1956, and the country's last polio epidemic was in 1961-62, after a second wave took hold due to vaccination rates not being high enough to achieve herd immunity.

Many of those who contracted polio in the 1950s, after leading active lives with what they considered the scars of a disease they'd survived, are now experiencing symptoms recognised as post-polio syndrome (PPS) and/or the late effects of

polio. The symptoms can include muscle weakness, pain and debilitating fatigue, with some people developing severe neurological symptoms.

As they grapple with a series of health challenges that many never anticipated, survivors have watched as the country has scrambled to contain the latest pandemic and **distribute vaccines** that were produced at light speed compared to the years it took to produce the first polio vaccine, a vaccine that for various reasons, they missed out on.



Gary Newton says ‘polio survivors are now the forgotten generation because we’ve lived two generations of not having the virus in Australia.’ Photograph: Alana Holmberg/The Guardian

## Gary Newton, Geelong

I’m the youngest of five kids. I was a healthy baby, learned to crawl and stand and walk by the age of nine months. Just after my first birthday, 15 months, in the summer of 1954, my older sister came home from school and went to get me out of my cot like she always did. But when she tried to lift me out I couldn’t raise my arms ... I was kind of like a rag doll. So that was the beginning of the journey. I had 32 days in complete isolation at Fairfield Infectious Diseases hospital.

*“Imagine putting your child into isolation for 32 days. No one to stop them crying”*  
*Gary Newton*

At that time, polio was a disease that came in waves, mostly during summer. Public places were closed down, like cinemas and pools, and there was a lot of fear. And there was a stigma associated with having a child with polio, I think



that was probably part of the reason why my mum and dad never really spoke to me about it. It was a fairly traumatic time, for many parents, not just mine. Imagine putting your child into isolation for 32 days. No one to stop them crying. I was left with permanent paralysis in my legs. So I've worn callipers or braces every day of my life.



Gary Newton has worn callipers every day of his life. Photograph: The Guardian

More recently, I've lost about 30% use of my arms. About five years ago, I started to read about people who were holding chickenpox parties [in order to deliberately infect children]. I thought, I don't think these people really know what preventable diseases can be like, I need to do something. Maybe I could use my voice to change people's perceptions of these diseases, which people have forgotten.

Polio survivors are now the forgotten generation because we've lived two generations of not having the virus in Australia. I don't dwell on what polio has taken away, I focus on what it has given me and the gratitude that I've got for all the things around me.



Gabe Mostafa lives with the late effects of polio. Diagnosed in 2020, he wasn't vaccinated when in Egypt, his country of birth. Photograph: Christopher Hopkins/The Guardian

## Gabe Mostafa, Melbourne

I was born in Egypt – Cairo – in 1958, and moved to Australia in 1967. I wasn't on a ventilator or anything like that, but my right side was affected. My sisters and brothers say that my body looks like Hercules on one side and the other half looks like Peewee. At the time I didn't go to hospital because mum thought they couldn't do anything for me. Mum kept me at home and basically looked after me and massaged my legs and arms – back then there was very little knowledge about polio.

*"I'm glad I didn't know it was coming though, I would've wrapped myself up in cotton wool"*

*Gabe Mostafa*

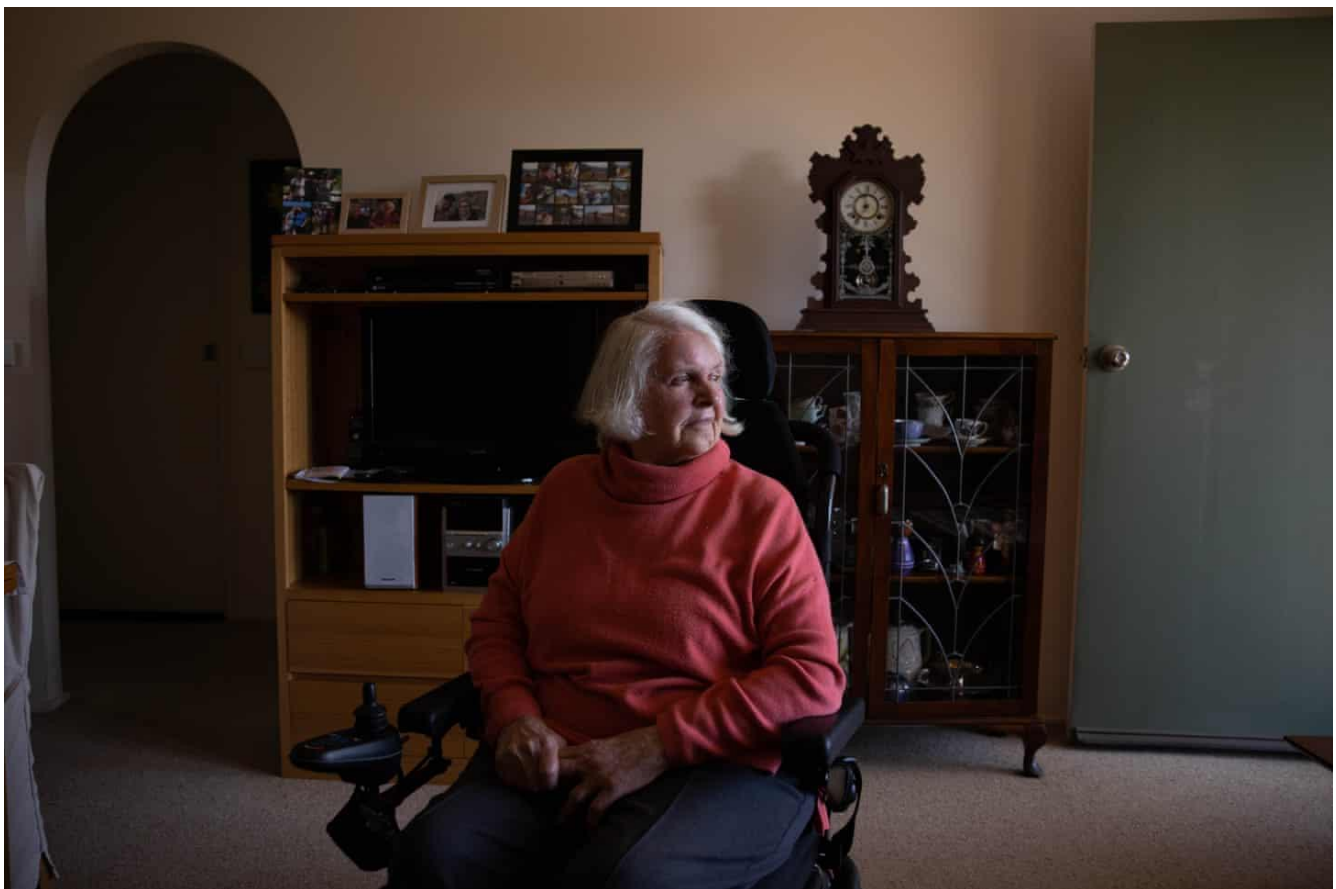
I learned to live with it and was very active in adulthood, I used to run 10kms a day, did things like helped a friend build a house. Now I'd be lucky to do any of that stuff because fatigue sets in and all I want to do is go to sleep. I started to get pain in my back, pain in my legs. But it wasn't until last year when I read an article about post polio or late effects of polio that I realised I ticked a lot of the boxes. They told me I'd need a back brace, and an arm splint. I'd been falling over a lot too. Earlier this year I bent over to pick up something at my office and I fell and really injured myself. My right side is very weak. My wife won't let me get my own dinner out of the oven. I can't carry it with both hands, and I could lose

balance. They're the things that are challenging now. I'm glad I didn't know it was coming though, I would've wrapped myself up in cotton wool.

Back in Egypt and Gaza, all my siblings and cousins used to go to the beach, and they'd all go out swimming but I was left sitting on the shoreline because I was in callipers. So when I eventually came out of the callipers I was like a bull out of a gate.

I asked mum a while back about how I contracted polio. All my brothers and sisters got the vaccine, but I couldn't – she told me, “you always had a cold, so you couldn't get in to get the vaccine”. And then I got it, I contracted polio. Mum used to sit for hours crying when I was a kid, one of my brothers told me recently.

My children went and got vaccinated [against Covid] recently. It wasn't an issue. Everybody in my family has been vaccinated.



Nola Buck at her home in Old Toongabbie. Photograph: Carly Earl/The Guardian

## Nola Buck, Sydney

I'm 86 years old. I was born in Broadford in Victoria, and then my father went to New Guinea during the war so we came over to Sydney to stay with my auntie and uncle. I contracted polio when I was about two and a half.

It was only as an adult after I started getting new symptoms that someone suggested I ask my parents for a bit of a brief history of when I contracted it. So I asked my mother to write a few things down. She took a big breath and said

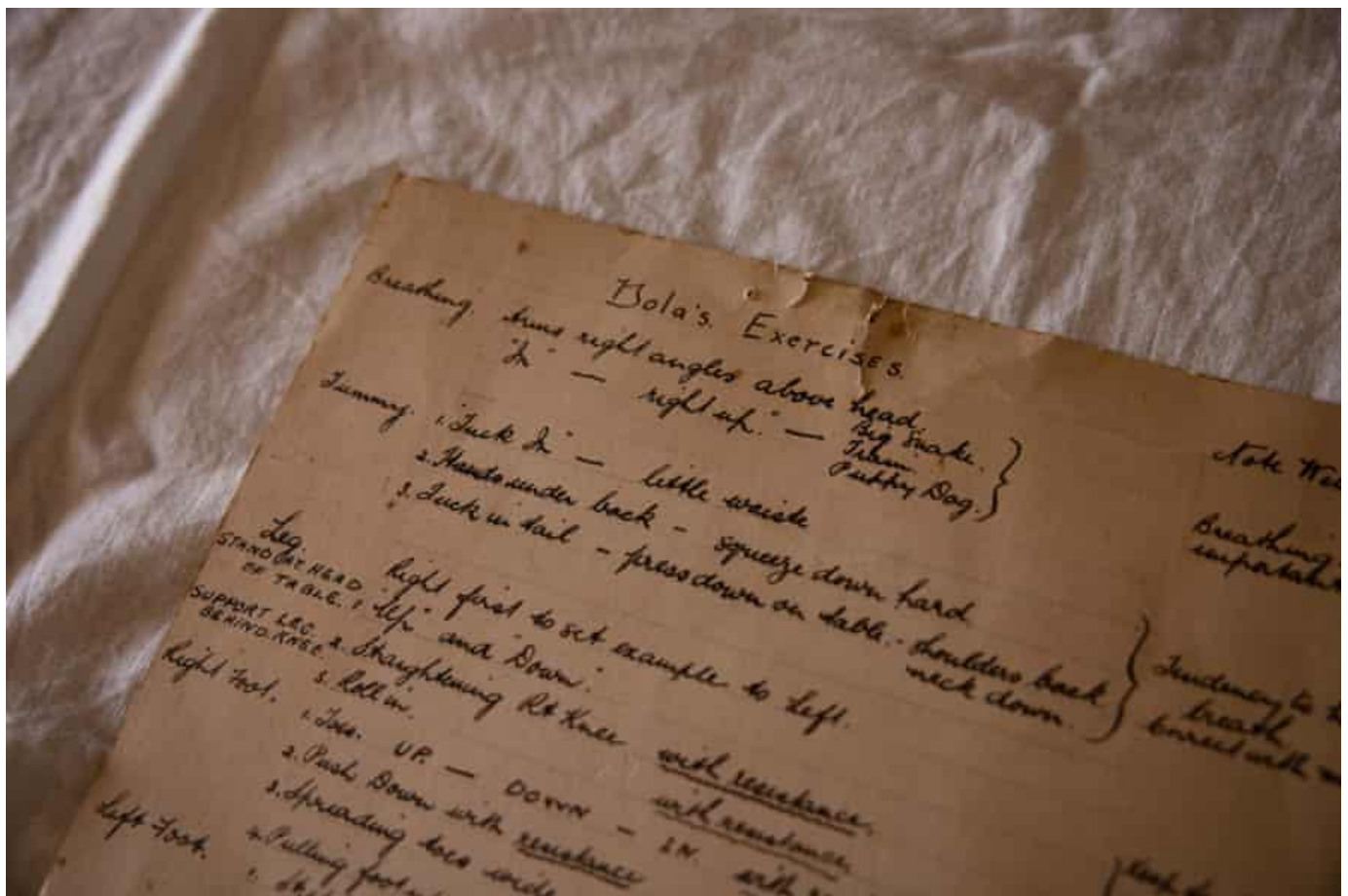


“well, here we go ...” It was obviously painful for her. There were two theories about how I contracted polio. One was from a traveling salesman, who was going around selling a calendar between Kilmore and Broadford. I still have that calendar. The other theory was that I caught it from the children next door that I used to play through the fence with.

*“I remember... mum bringing the baby to visit and as she walked away to leave, I was just screaming”*

*Nola Buck*

I was away for rehabilitation for about three to four years on and off. While I was away my younger brother was born and that’s one of the memories I remember about hospital ... mum bringing the baby to visit and as she walked away to leave, I was just screaming ... When I came back, I still wasn’t walking. So someone used to come in and help with the house work while my mum gave me the exercises. I still have the big chart, the list of exercises she had on the wall.



Nola Buck still has the exercise schedule given to her mother by the doctors. Photograph: Carly Earl/The Guardian

As a kid I didn’t really know anyone else with polio, and I didn’t really think about it. My grandmother remembered people would cross to the other side of the street when they saw her. I could never walk very far. I knew that I could never jump, but I was always pretty good, you know, I studied at uni, I travelled a lot, in my twenties I hitchhiked around England. When I started getting new symptoms in my sixties, fatigue and such, I hadn’t put it down to anything like

the late effects of polio. I got married when I was 34 and had four children. So this is what I'd put the fatigue down to. It's very hard to distinguish sometimes between the effects of ageing and the effects of having had polio.



Lyn Lillecrapp contracted polio as a newborn, and still swims three to four times a week. Photograph: James Elsby/The Guardian

## Lyn Lillecrapp, Adelaide

I caught polio when I was six weeks old. Really young. But the best way to do it. Because I've not known anything else. Some people I know caught it when they were eight and older and they had to relearn life. I was about 18 months old before it was actually diagnosed as polio. My parents realised something was wrong because I wasn't kicking off my blankets. They took me to see [renowned doctor] Dame Jean McNamara and she confirmed it. She said, "well, I will get her up and walking," and at 24 months, I was walking with callipers. I graduated to crutches and stayed on them for 40 years until the doctors recommended the permanent use of a wheelchair because of the damage to my shoulders and elbows.

My mum left home when I was eight years old. She couldn't handle the thought that it was going to be a lifelong job. I sometimes wonder if one of the reasons she left was the local chatter as to what she did that led to me catching polio. I was the only case at that time. "Small town" talk in those days was very much in place. My father raised me. We actually just got on with life. He had the attitude that



this is a cruel world, it isn't going to change for you – you have to learn to live in it.

I contacted my mother again when I was about 19. She was still very embarrassed about it and for a number of years kept introducing me as her niece. We were never close. She didn't cope with sickness.

Dad died when I was 18 and I was out in the big wide world by myself. I worked at the Department of Defence for 42 years. I'm a swimmer. I still swim three to four times a week with a senior squad in my local club. I represented Australia at 10 international sporting events. I do all four strokes and then put them all together in the medley.

I was vaccinated for polio when I was 11. We didn't get a choice. That was 1966. We were pushed into a crocodile line at school, marched down to the local clinic and jabbed. None of us had any problems. There were no conspiracy theories.



Gayle Kennedy was born in Ivanhoe NSW. She is a member of the Wongaiibon Clan of the Ngiyaampaa speaking Nation of south-west NSW. Photograph: Carly Earl/The Guardian

## Gayle Kennedy, Sydney

I was born in Ivanhoe, New South Wales in 1955. I contracted polio when I was two years old and had to be sent away from the family [for treatment]. It was

about three years before I went back to my family. It was just a different world. I didn't even realise I was black. It's pretty much the same for other survivors who had long stints away from their family ... People forgetting their language, forgetting their ways. It was very disruptive. One minute living a fairly carefree, easygoing Aboriginal lifestyle, and then back to hospital life.

*"I went into a deep depression. But I allowed myself that. I allowed myself the sadness"*  
*Gayle Kennedy*

It's a lonely thing being a polio kid ... A lot of polio people end up being very creative and living inside their heads. I spent some time in an iron lung. When I came to Sydney as a young adult I met like-minded people that were into music and the arts, and I just made a different life for myself, an amazing life. But post-polio syndrome virtually stopped me in my tracks when I was about 55. I was very active, I had a well-paid job with the NSW attorney general's department, but I had to leave because of the intense fatigue. And that's when I decided to become a writer.

Post polio is horrendous. You think that you've gone through all the bad times and suddenly you find yourself getting weaker and begin experiencing pain and brain fog and fatigue. I went into a deep depression. But I allowed myself that. I allowed myself the sadness ... Eventually, I started to build a new life for myself. And I've done all my traveling overseas in a wheelchair.

At 66, I'm one of the youngest survivors. But people have forgotten about polio, they've forgotten that we're still here, dealing with the after-effects. It annoys me immensely when I see people raging against vaccines ... Don't they realise that these diseases could take hold again? That's a thing that terrifies me. I worry that there could be another outbreak. It's possible, because it's always there. It's kept at bay by vaccinations.

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