

# Polio Oz News

March 2022 – Autumn Edition

## New MRI Technique

**By Michael Jackson**

*Polio Australia Clinical Educator*

### **New MRI Technique Detects Spinal Cord Gray Matter Atrophy in a Study of Polio Survivors**

A research article accepted for publication on the first of this month by the European Journal of Neurology is worth noting in this edition of *Polio Oz News*. In short, a new MRI technique being utilised in Switzerland called rAMIRA is able to provide spinal cord cross-section images of increased clarity, and in 20 polio survivors in a research project utilising the technique, spinal cord gray matter changes were detected.

The spinal cord – that part of the nervous system which transmits signals to and from the limbs and trunk – is a long tapering cylinder shape, roughly the dimensions of a HB pencil (but much longer!). A standard MRI image, as amazing as it is, cannot provide an image with enough resolution to measure such a small area reliably enough to detect volume changes. The resolution problem is also due to movement, both voluntary and physiologic.

What the rAMIRA technique does differently is that it captures images *in relation to heartbeats*. To achieve this, they have a pulse monitor on the person in the MRI and then program the machine to capture images at the most still time between heartbeats. Although this takes longer to acquire the images, it was determined to be a feasible amount of time to do so.

What the researchers found with the improved images they obtained was twofold:

- polio survivor subjects had spinal cord gray matter atrophy versus control subjects; *AND*
- polio survivor subjects who were experiencing post-polio weakness and functional changes had significant atrophy compared to polio survivor subjects NOT experiencing changes.

The authors concluded that a secondary neurodegenerative process is occurring in those experiencing the symptoms of PPS, independent of their age and the neurological damage from their acute polio.

What this amounts to for post-polio education

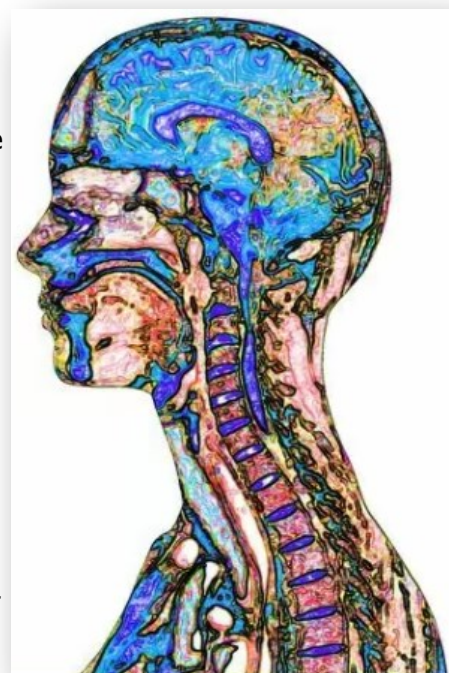
and understanding, is that evidence of spinal cord anatomy change is detectable and significant, **AND** it correlates with muscle weakening and functional declines in those experiencing PPS symptoms. Other imaging research in 2021 (Shing et al., *Cerebral changes in post-polio syndrome: A quantitative MRI study*)

showed changes in the brains of polio survivors. Combined, these articles add evidence to our understanding of the neuroanatomical changes induced by acute polio and post-polio syndrome.

This advancement in MRI technique is comparable to how the power of traditional microscopes enabled bacteria but not viruses to be seen, whereas the electron microscope (developed in 1931) enabled viruses to be seen for the first time. This development has the potential to expand our understanding of neuroanatomical changes in many conditions and become a tool in the detection and diagnosis of post-polio conditions.

Wendebourg, M.J., Weigel, M., Richter, L., Gocheva, V., Hafner, P., Orsini, A.-L., Crepulja, V., Schmidt, S., Huck, A., Oechtering, J., Blatow, M., Haas, T., Granziera, C., Kappos, L., Cattin, P., Bieri, O., Fischer, D. and Schlaeger, R. (2022), *Spinal Cord Gray Matter Atrophy is associated with functional decline in Post-Polio Syndrome*. *European Journal of Neurology*. Accepted Author Manuscript.

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**Polio Australia**

Representing polio survivors

PO Box 2799  
North Parramatta NSW 1750  
Phone: +61 3 9016 7678  
contact@polioaustralia.org.au

President—Gillian Thomas OAM  
gillian@polioaustralia.org.au

Vice President—Gary Newton  
gary@polioaustralia.org.au

Secretary—Maryann Liethof  
maryann@polioaustralia.org.au

Treasurer—Alan Cameron  
alan@polioaustralia.org.au

Editor  
Maryann Liethof  
editor@polioaustralia.org.au

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“Autumn is the mellow season,  
and what we lose in flowers we  
more than gain in fruits”  
~ Samuel Butler ~

**Polio Australia's Websites**

**Polio Australia**  
Representing polio survivors throughout Australia

Welcome to the Polio Australia website. Polio Australia is a not—for—profit organisation supporting polio survivors living in Australia. This website contains information about polio, the Late Effects of Polio, the work of Polio Australia and much more.

[www.polioaustralia.org.au](http://www.polioaustralia.org.au)

**Polio Australia**  
Improving health outcomes for Australia's polio survivors

The Polio Health website is a comprehensive resource for both health professionals and polio survivors. It contains clinically researched information on the Late Effects of Polio; the Health Professional Register; and where Polio Australia's Clinical Practice Workshops for Health Professionals are being held.

[www.poliohealth.org.au](http://www.poliohealth.org.au)

**Australian Polio Register**  
Have you added your polio details?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. To make the Australian Polio Register truly reflective of the unmet need for polio services throughout Australia, we urge every Australian polio survivor to join the Polio Register. Our strength lies in our numbers—please help us to get you the services you need by adding your polio details to the Register. You can register online or by downloading and completing a [paper copy](#).

[www.australianpolioregister.org.au](http://www.australianpolioregister.org.au)

## President's Report



**By Gillian Thomas OAM**  
President

Welcome to 2022, which has already been hit by major floods in Queensland and New South Wales, and, tragically, war in Europe. As a well-seasoned and optimistic polio survivor, even I have found it difficult to pick out the

positives in the daily news reports.

Having said that, I do find it heartening that the dedicated team at Polio Australia are still able to pump out such useful resources for our post-polio community. As you will see throughout this edition of *Polio Oz News*, Michael continues to generate new opportunities to educate health professionals; Paulette is keeping the databases relevant (P6); and Steph has a new Community Development colleague, Devalina (P4), who brings a range of useful skills and experience to the role.

As I have been in the unavoidable position of needing to stay in a respite care facility since early December 2021, I am keen to see an uptake in the free *Aged Care eLearning Course* that Michael has developed (P6). I gave it a test run myself and believe that anything that can

help personal care workers learn more about the needs and personalities of polio survivors, the better our future will be! This also goes for the new *Post-Polio Hospital Kits* (P7) which will be distributed to 100 hospitals across Australia in June this year.

I am very pleased to congratulate Polio NSW's Nola Buck, who received her recognition for service to people with a disability and the community in the Australia Day Honours list. A posthumous OAM was also awarded to the late Brett Howard, Polio SA's President and Polio Australia's Treasurer. Although always humble, Brett would have been delighted to receive it.

We were also very saddened to learn of Neil Balnaves' untimely death (P 15). Neil was a polio survivor and a great friend to Polio Australia. Through his charitable Foundation, Neil provided funding to enable us to employ Maryann as our National Program Manager from 2011-2013. This seed funding enabled us to establish the strong organisation that Polio Australia has become today. Neil's contribution has been an enduring legacy to polio survivors across Australia. See [online](#) for details of Neil's generous support for Polio Australia. Our sincere condolences to Neil's wife, Diane, and to his son, Hamish, with whom we also worked closely. 🌈

Gillian

## From The Editor



**By Maryann Liethof**  
Editor

What trying times we live in, eh? But haven't we always faced challenges throughout the years which, somehow, get the sharp bits knocked off the edges with time? I live in hope!

Stories like the one told about *Melbourne's Former Infectious Diseases Hospital* (P8), serve to remind us that things have come a long way since the days of the polio epidemics of last century—or have they? I'll let you decide.

I think Steph's article—*Emerging Out Of Lockdown* (P10)—is something we can all learn something from. Of course, we may have read this information before, but have we actually taken the extra step of incorporating it into our lives? Maybe now is exactly the right time to consider our 'new normal'.

Queensland polio survivor, Robynne Clifton's, story of being *Forgotten After A Cyclone* was a very timely reminder of how being a good neighbour can literally be the difference between life and death for some people. One of Polio Australia's Board Members sent us an email this week letting us know that she had been without

power for 7 days due to the Queensland floods. And it was thanks to her "lovely neighbours" that she is able to start with the clean up.

I found the article *Pandemics Disable People* (P16) a comprehensive and thought provoking exploration of how all kinds of infections can change lives years after the event, and what that might mean for 'survivors of COVID-19'.

However, having survived polio has convinced many people that both they and their loved ones should make the most of whatever vaccines are available. This is evident in the *Esther Missed Out On The Polio Vaccine* article (P20). Now living in South Australia, Esther was born in South Sudan where the polio vaccine was not available to her. Now raising two young daughters, Esther is keen to ensure they are vaccinated against COVID-19.

We are very concerned with WHO's announcement of the first case of wild poliovirus in Africa in five years (P21). With so much else going on in the world, this will need to be closely monitored. Along with the tragedy unfolding in Ukraine (P22), where a polio outbreak may be the very least of their problems.

Please keep safe, and try practicing random acts of kindness if and when you can. 🌈

Maryann



## 2021 Program Update: Clinical Practice Workshops



**By Michael Jackson**  
*Polio Australia Clinical Educator*

The new year brings optimism that we may have seen the worst effects of the coronavirus pandemic on the delivery of workshops to professionals – the primary activity of this program. Managing COVID as an endemic virus is projected to reduce most (but not all!) barriers to travel

Workshops are now not all delivered in-person and onsite (unlike in 2017-2019), and so three modes of delivery have emerged. Each mode covers the same core content, with variability of other content based on the health disciplines attending, and two are modified for duration. All workshops are presented *live*, and most include a Lived Expert polio survivor sharing their story for 10 to 15 minutes.

The three workshop modes are:

- 1) In-person: an on-site workshop, physically with the audience, at their location.
- 2) Remote: an online Zoom/Teams/WebEx workshop delivered live to a specific location or district's audience, who are from the same organisation.
- 3) Monthly Online: an online Zoom workshop, occurring on the second Tuesday each month, open to any clinician in Australia, and always two hours long.

Since the last issue of Polio Oz News, one *In-person Workshop* was delivered in Springfield QLD, two *Remote Workshops* delivered (for Ballarat VIC orthotists, and Warriewood NSW Aged Care staff), and two *Monthly Online Workshops* were delivered. Had we only continued with one mode (in-person, onsite) we would have delivered only one workshop since late November.

A total of 26 health professionals were trained at the five workshops, which seems a low average,

but this was mostly due to only two attending each of the Monthly Online workshops during the Silly Season.

Looking ahead to bookings for this half-year, we reached out to over 120 facilities in early 2022 and some resulted in conversions to scheduling workshops. Hospitals and clinics' confidence related to booking workshops was very limited during last December and remained low in January due to a shift towards the coronavirus being managed as an endemic disease, and the Omicron wave peaking in late January/early February.

Workshops currently scheduled:

- 5 x In-person Workshops scheduled up until end of this FY (VIC, NSW)
- 5 x Remote Workshops scheduled in 2022 (VIC, TAS, NSW)
- 4 x Monthly Online Workshops

Securing a workshop still relies on facilities being confident in hosting a workshop in their local and state health environments, and in non-COVID clinical education rebounding from a two-year low-priority status. Confidence appears to be improving faster at the private clinic level than within large facilities or systems.

This financial year (2021-22) we should reach over 50% on each of the benchmarks for the program, which are: 800 professionals trained and 55 workshops per financial year. We are on target, with 201 professionals and 19 workshops from June-December 2021.

In closing, we recognise that the workshop program funding for the current three years will end in just over four-months' time. Despite it being an unprecedented last three years, our communications regarding the program with the Department of Health have been consistent and positive, and our reports have shown the considerable work and impact the program projects have made. We have already requested further funding, and look forward to a determination in Polio Australia's favour to continue the work of the program for a further three years. 🌟

### New Team Member: Devalina Bhattacharjee

My background is in healthcare, having worked as a General Practitioner in India for many years before specialising in public health. I have worked with and treated many patients of polio in my role as a GP. On a personal level, I am very passionate about advocating for, and raising awareness about Late Effects of Polio, having seen my aunt struggle with it as a survivor.

My role as a Community Development Worker is going to centre around delivering community information sessions and rendering logistic support. In the short duration I have been with Polio Australia, I find myself incredibly moved and inspired by the journey that each member of our wonderful post-polio community has undertaken; surmounting multitudes of obstacles with the utmost of courage and grace. It is my hope to be able to do justice to the position by focussing my energies on supporting polio survivors to make their presence felt and getting their needs addressed. 🌟



## Community Programs Update



**By Steph Cantrill**  
*Community Programs Manager*

Is it too optimistic to feel like the end of pandemic interruptions is, finally, just around the corner? COVID-19 isn't over, but perhaps we're heading into "Covid normal" and working out what that means. Anyway, my key point is this: in-person sessions are back on the table!

We will, of course, continue to monitor the situation and adjust our plans as necessary in line with restrictions. And we do understand that there may be some hesitation about meeting face-to-face, and will therefore continue to meet online.

### Welcome Devalina

But first, the exciting news! We're very pleased that Devalina Bhattacharjee (P 4) has joined the team as our new Community Development Worker. She's settling in nicely, despite our staff being spread across the country. I'm very excited to be working together with Devalina on our upcoming info sessions.

### Community Information Sessions

- **In-person sessions:** Our first "tour" will be in South Australia, beginning with a seminar event in Adelaide on the 21<sup>st</sup> of March and information sessions in Victor Harbor (22<sup>nd</sup> March) and Port Augusta (24<sup>th</sup> March). You can find more information about these sessions – and register if you're local! – at [www.polioaustralia.org.au/community-information-sessions](http://www.polioaustralia.org.au/community-information-sessions).
- **Monthly Zoom sessions:** we continue to meet monthly on Zoom. Join us any time – it's a great way to connect and learn from others! First Monday of every month, 11.00am AEST/AEDT (NSW/ACT/Vic/Tas).
- **NDIS and My Aged Care Zoom chats:** these have been really valuable for shared learning and support. We will continue these sessions on a roughly quarterly basis. The next ones will be:
  - NDIS on 5<sup>th</sup> April at 11:00am AEST
  - My Aged Care on 12<sup>th</sup> April at 11:00am AEST

### Webinars

We have a few upcoming webinars/other chats:

- **Late Effects of Polio overview:** Tuesday 8th March at 11:00am AEDT
- **Managing Post-Polio Pain with Dr Stephen de Graaff:** Tuesday 15th March at 11:00am AEDT
- **Smart Home Devices with Assistive Technology Australia:** Tuesday 29th March at 11:00am AEDT

**\*\*Register for all Zoom chats, webinars and information sessions at:**  
[www.polioaustralia.org.au/community-information-sessions](http://www.polioaustralia.org.au/community-information-sessions).\*\*

### Resources

- **Blog:** don't forget we have a [blog](#)! Recent blog posts include a guest post on managing fatigue from staff at Advanced Rehab Centre, and step-by-step guide to Zoom.

### Advocacy/Awareness-Raising and Lobbying

- **NDIS exclusion:** we support Spinal Life Australia's [Disability Doesn't Discriminate](#) campaign, and congratulate them on reaching over 20,000 signatories to the petition (at the time of writing). We absolutely agree that all people with disability should have access to the care and support they need, no matter what their age.
- **Assistive Technology For All (ATFA):** a range of campaign materials are nearing completion with the [ATFA Alliance](#). There will soon be a letter-writing campaign, and you can join the [Facebook group](#) to stay informed and learn how you can get involved. Polio Australia's involvement with ATFA is concurrent with our support of the Disability Doesn't Discriminate campaign.

### Social Media

If you're on social media, stay connected! We regularly update our [Facebook page](#) with news and information. And our [Polio Australia group](#) is a platform for you to share news and ask questions. We also have the [NDIS Hub Facebook group](#) for the younger ones. Come and join us!

And, if that just isn't enough social media, you can always view our videos on our [YouTube channel](#), and follow us on [Twitter](#).

I hope you are all staying well, and very much look forward to connecting – either online or in person – in the near future.🌟

Author of several polio books, also editor of Mornington Peninsula PPSG and Polio Network Victoria's newsletters, Fran Henke, has published a new novel: ***The Coriolis Effect*—[www.franhenke.com](http://www.franhenke.com)**

*The Coriolis Effect* is book four in what was to be a trilogy (she couldn't help herself). Set in 1900, largely on a steam ship from Genoa to Geelong, Phoebe Anderson, author of a book about appalling treatment of orphans in Australia, has been to London for passage of the Federation Bill. On the way home she faces life changing challenges and opportunities. The Coriolis Force is a fictitious force acting on objects in motion – the effect is the heart of the story.

## Polio Australia's Research Database



**By Paulette Jackson**  
Administration Officer

Did you know Polio Australia has a database of research relevant to polio and post-polio conditions? This extensive database is for use by clinicians, polio survivors and those interested in exploring post-polio topics. During 2021 alone, there were 19 new research studies published pertaining to polio or post-polio conditions (see Table on right). We recommend that clinicians who work with you are made aware of this resource.

Michael's article in this issue of *Polio Oz News* (P 1), explains a recent research study published in February 2022. This study, focusing on imaging post-polio changes, will soon be added to Polio Australia's research database along with future relevant research articles.

Check out our full database here: [www.poliohealth.org.au/research-categories/](http://www.poliohealth.org.au/research-categories/) where you can search by category. 🌐

Title	
1	Construct Validity And Reproducibility of C-Mill Walking-Adaptability Assessment in Polio Survivors
2	Living the Present with an Enemy from the Past: The Role of Noninvasive Ventilation in a Poliomyelitis Survivor
3	Risk factors for functional deterioration in a cohort with late effects of poliomyelitis: A ten-year follow-up study
4	Post-polio syndrome and the phantom of acute previous poliomyelitis: a systemic entity
5	Neuronopathies and Sleep Disorders: Spinal Muscular Atrophy, Amyotrophic Lateral Sclerosis and Post-polio Syndrome
6	A Longitudinal Motor Unit Number Index (MUNIX) Estimation Study in Poliomyelitis (2815)
7	Treatment with L-Citrulline in patients with post-polio syndrome: A single center, randomized, double blind, placebo-controlled trial
8	Knowledge of healthcare professionals about poliomyelitis and postpoliomyelitis: a cross-sectional study
9	Imaging data indicate cerebral reorganisation in poliomyelitis survivors: Possible compensation for longstanding lower motor neuron pathology
10	An algorithmic approach to total hip arthroplasty in patient with post-polio paralysis and fixed pelvic obliquity
11	Falls in Post-Polio Patients: Prevalence and Risk Factors
12	Fall-Related Activity Avoidance among Persons with Late Effects of Polio and Its Influence on Daily Life: A Mixed-Methods Study
13	Paralysed with Fear a Literature Review on Aspects of Pregnancy in Polio Survivors
14	Effects of muscle strengthening and cardiovascular fitness activities for poliomyelitis survivors: A systematic review and meta-analysis.
15	Polio survivors have poorer walking adaptability than healthy individuals
16	Effectiveness of Intravenous Immunoglobulin for Management of Pain in Patients with Postpolio Syndrome
17	Cerebral changes in post-polio syndrome: A quantitative MRI study
18	Total Hip Arthroplasty in Patients With Postpolio Residual Paralysis: A Systematic Review
19	Quality of life in Hungarian polio survivors

## Free Aged Care eLearning Course



In 2021 an online course suitable for non-clinicians in the Aged Care workforce was developed. Since the last Board Meeting this course has been reviewed internally and by two Aged Care workers, with the feedback provided being used to improve access procedures, modify content, add features, and correct errors.

This course, like the workshops, is **free**. While it is oriented to personal care workers (PCWs) in Aged Care, the course and its content is open to anyone seeking further knowledge on helping those with post-polio conditions (workshops are still recommended for licensed clinicians). If you have a carer not working in Aged Care they may find it both relevant and helpful, as might your spouse, and so they are encouraged to complete it for your benefit!

The course consists of 15 lessons with two-

question quizzes, and a final five-question quiz (which enables a certificate of completion to be issued). The course takes just under two hours to complete, and does not have to be done all at one time.

After 4 to 10 months of data gathering, the potential for developing similar courses for clinicians (and other audiences) will be considered.

The projected trends for professional education such as ours point to the online mode of delivery becoming both more desired and utilised by workers towards 2030. These trends emerged before the pandemic, but were accelerated by the social restrictions presented by the pandemic.

This course has some final editing prior to release next week. Organisations in the Aged Care sector will be notified so that they can share the course with their employees. We will also commence advertising on social media platforms, and in audience relevant magazines and websites for Aged Care workers. 🌐

[www.poliohealth.org.au/diagnosis-and-management/](http://www.poliohealth.org.au/diagnosis-and-management/)



## Financial Update

Polio Australia would like to thank both individuals and organisations for their generous support of **\$422.00** for the first quarter of 2022. Be assured that 100% of these tax-deductable donations are used to support Australia's post-polio community.

If you would like to see how your 'living bequest' can support polio survivors now, click on the following link: [www.polioaustralia.org.au/donations-bequests/](http://www.polioaustralia.org.au/donations-bequests/) or contact the Polio Australia office on Ph: 03 9016 7678 or Email: [contact@polioaustralia.org.au](mailto:contact@polioaustralia.org.au).

## Hospital Kit Project

**By Michael Jackson**

*Polio Australia Clinical Educator*

One 'contextually positive' effect of the pandemic on our Professional Workshops program was an underspend of funds, mostly due to the reduction in travel spending over the last two years. As a result, we were required to nominate projects to the Department of Health where the unspent funding would be utilised within the program.

The major project of the handful nominated was the development and distribution of *Post-Polio Hospital Kits* across Australia. This project involves curating, updating and printing our post-polio resources suitable for hospital clinical departments, and then assembling and distributing the 100 kits to large and regionally important hospitals.

Many of the simpler resources and kit elements are ready, but completing the kits is pending the updating and printing schedule of multi-page documents. The kits will have three folders with discipline specific resources – one folder for each of three common hospital departments (medical, nursing, and allied health).

The project should be finished in May this year, with hospitals receiving their kits in June 2022.

If you have an association with a large or regionally important hospital, please express your knowledge of the kits, and your desire that they be put to good use and conveniently stored for the clinicians who may work with you. 🇦🇺





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## Melbourne's Former Infectious Diseases Hospital

By Joseph Dunstan

Source: [www.abc.net.au](http://www.abc.net.au) – 6 February 2022

*The following is an excerpt from an article which can be linked to from [here](#).*

A generation of polio survivors endure well-meaning but 'sinister' treatments.

But in the decades that followed, the hospital began to build its expertise and reputation as a centre of excellence for the treatment of infectious diseases, including the influenza outbreak after World War I.

That was followed by the polio epidemic, which the hospital prepared to combat with a supply of "iron lung" ventilators from London.

The disease, which can present as a flu, is devastating for a small number of patients, and hit children especially hard.

People are worst affected when the virus reaches the nervous system, paralysing muscles including the diaphragm or limbs.

There's a familiar ring to a note around this time from the hospital's medical superintendent, F.V. Scholes, where he described the pressures of the epidemic.

*"Not only were the majority of the older and more experienced nurses required for the Poliomyelitis wards, in which, particularly in the respirator wards, a large staff had to be maintained, but very careful nursing and isolation measures were necessary in the Diphtheria and Scarlet Fever wards to prevent infection there," he wrote.*

*"Finally, several hundred patients were admitted as suspected cases of Poliomyelitis, found actually to be suffering from a wide variety of diseases, and for many months, all the isolation accommodation in the hospital was taken up."*

Polio would continue to pose a challenge to humanity worldwide for decades to come.

Vaccines were produced in Australia from the 1950s onwards, [but it wasn't until 2000 that the Western Pacific region, including Australia, was declared polio-free.](#)

Former nurse Robyn Abrahams was three when she was infected amid one of the community's "roaring epidemics".

The 71-year-old recalls being taken into a "big white ambulance with four men in white coats" who drove her to Fairfield Infectious Diseases Hospital, where she remained for many months in isolation.

*"I can remember my mother as they shoved me in the back of the ambulance, was screaming 'I love you, I love you, I love you'," Ms Abrahams said.*

She also remembers the stigma that came with the disease, which is spread through faeces and mucous like most gastrointestinal viruses.

*"There was a lot of blame, it was said to be 'dirty people' got it, and things like that," she said.*

The fear and top-down, authoritative culture that pervaded medical institutions at the time also looms large in her memory.

She was told she was in an iron lung for a while, and she can recall hearing the "whoosh, bang, whoosh, bang" of the machines working throughout the hospital.

But her main memories are of seeing her visiting parents through glass and nurses in long white dresses who administered fairly 'sinister' treatments that focused on getting the patient moving, but took little account of their psychological health.

*"Best as they knew at the time, Fairfield and other places did the very best job they could," she reflected.*

Despite the traumatic illness which lingers to this day in the form of [post-polio syndrome](#), Ms Abrahams went on to become a nurse and regards herself as having enjoyed a "wondrous life".

She and other senior polio survivors, [many of whom are campaigning for inclusion in the NDIS](#), are keen to see Fairfield maintained with a museum or educational centre added to the site to ensure their story is not lost. 🇦🇺

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# DID YOU OR SOMEONE YOU KNOW HAVE POLIO?

## FREE COMMUNITY INFORMATION SESSIONS

ADELAIDE (SEMINAR)

21st MARCH

VICTOR HARBOR

22nd MARCH

PORT AUGUSTA

24th MARCH

### THE INFORMATION SESSIONS WILL COVER:

Current information about the Late

Self-management strategies

Effects of Polio

Q&amp;A

What to tell your health professional

Local connections

### RSVP ESSENTIAL - FOR MORE INFO OR TO REGISTER:

ONLINE: [www.polioaustralia.org.au/community-information-sessions](http://www.polioaustralia.org.au/community-information-sessions)CONTACT US: 0466 718 222 OR [devalina@polioaustralia.org.au](mailto:devalina@polioaustralia.org.au)

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## Polio Survivors On Australia Day Honours List

### Brett Ian Howard OAM

" Awarded the Order Of Australia Medal for  
his dedication and devotion to powerboat  
racing and to the community "



We thank Adelaide Speedboat Club for sharing the news of **Brett Howard** being awarded the Order of Australia Medal in the Australia Day Honours list.

Brett was nominated for his dedication to powerboat racing and within the broader community.

Brett was President of Polio South Australia for more than 10 years and also served on the Board of Polio Australia.

We are forever grateful for his dedication to us and the polio community.

Sadly, Brett passed away on June 5th, 2020. He had been previously nominated by

Polio SA, so we are pleased that Brett finally received this recognition—and for Brett's family to be able to honour and celebrate his memory for all the work he did.

Congratulations also go to **Nola Buck** from Polio NSW, who also received Order of Australia Medal in the Australia Day Honours list. Nola received her recognition for service to people with disability and the community. 🌈

## Emerging Out Of Lockdown

**By Steph Cantrill**

*Community Programs Manager*

**Source:** [www.polioaustralia.org.au/emerging-out-of-lockdown/](http://www.polioaustralia.org.au/emerging-out-of-lockdown/)

### **Adjusting to a new routine or stepping back into the old one**

With lockdowns, restrictions, and the recent COVID-19 outbreaks, many of us have been spending a lot more time at home over the last two years. But how do we make sure we come out strong on the other side? This post contains a few suggestions – but remember, everyone's different. You need to do whatever works best for you!

#### **Changes to routine**

Whether it's underdoing or overdoing, changes to what's normal for you can have a big functional impact. Our clinical health educator talks about polio survivors' balance of activity and routine as like walking on a narrow ridge line – you don't have much scope for movement before you really notice the impact. For others who don't have disability or chronic illness, it's more like walking on a wider path – big changes will be noticeable, but they can ride out little alterations to their routine without feeling it too much.

You might find yourself trying to "catch" up on all the things you missed out on – whether that's exercise, social activity, hobbies, or even medical and personal appointments. But that's probably not the best idea. It's better to take it one step at a time.

You might want to prioritise, so that you don't get too overwhelmed and try to do everything at once. Which of the things you've missed out on should come first? Which things can wait a while?

#### **Time marches on**

As well as recognising that changes to your routine will have affected you, it's also worth noting that it's been about two years. If you're dealing with progressive changes due to Late Effects of Polio, it's likely that things may have changed in that time anyway. Here's some research to explore that a bit:

- Loss of motor units and strength – [a 2014 study](#) found a 20% loss of motor units and 15% reduction in strength over 10 years among polio survivors.
- Changes in mobility – [another 2014 study](#) (possibly the same cohort?) found average walking capacity declined by 6% over ten years, and self-reported mobility reduced by 14%. But for almost a fifth of the cohort

studied, walking capacity reduced by 27%, and self-reported mobility by 38%. That's quite a big change.

- Reduction in activities of daily living (ADL) – [a third study](#), from 2021, noted a reduction in ADL performance, including indoor and outdoor walking and eating, over a ten-year period. However, this study didn't assess things like housework. Still, it once again shows us that things can – and do – change over time.

Two years isn't much compared to a whole decade, but it's not nothing. Because you haven't been doing all the usual things you'd normally be busy with, you might not notice any reduction in function. But when you start to get back to doing all the things you were doing before, some changes might become evident. This is just something to be aware of – and something you might need to adapt to.

#### **Reassess your capacity**

As you start to get back into normal daily life, it might be worth taking stock of your current function, and making any necessary changes in response to what you're able to tolerate.

Some people might get an assessment every now and again at a rehab facility or polio clinic. Here you can have a formal review of your muscle strength, fitness, walking etc. If that's you, now might be a good time to make that appointment. (If you're thinking it might be good to be assessed by a health professional who knows something about polio, try searching our [health professional register](#).)

For a self-assessment of your capacity, an activity diary can be a useful tool. Here's how it works:

- Write down all the things you're doing over a week or two, and how long you spend on each activity.
- Rate your energy (or pain) levels out of 10.
- This helps you to see what you're doing – and what you're overdoing. The idea is that it gives a summary of what you're able to tolerate.

[This video](#) explains a bit more about activity diaries, and here's a sample (see Table on P 11).

This (hypothetical) person has written down what they did and for how long. I've categorised the activities into things that are fatiguing in **red**, restful in **green** and somewhere in between in **orange**. You'll see their energy went up and down a bit, but they clearly overdid it and had to spend the entire afternoon in bed. We often refer to this as "**boom and bust**".

## Emerging Out Of Lockdown *(cont'd from P 10)*

Time	Activity	Duration	Energy
0800-0900	<b>Shower + dress</b>	30 min	4/10
	<b>Breakfast</b>	30 min	5/10
0900-1000	<b>Gardening</b>	60 min	3/10
1000-1100	<b>Still gardening</b>	30 min	2/10
	<b>Take washing off line</b>	30 min	1/10
1100-1200	<b>Prepare/eat lunch</b> <b>Crash!</b>	20 min	0/10
1200-1300	<b>Bed</b>	60 min	0/10
1300-1400	<b>Bed</b>	60 min	0/10
1400-1500	<b>Bed</b>	60 min	0/10
1500-1600	<b>Bed</b>	60 min	0/10
1600-1700	<b>Bed</b>	60 min	0/10
1700-1800	<b>Bed</b>	60 min	2/10
1800-1900	<b>Eat leftovers</b>	20 min	2/10

As you see, this person spent an hour and a half gardening, even though they were pretty much spent after the first hour. Sometimes it's tempting to just get things done and then it's done. But you can pay for that, as I'm sure you know.

I will add that there will always be some things, like a major event or family gathering, that you might choose to prioritise even though you know it'll exhaust you. That's up to you, and as you learn your limits you'll also learn ways of managing that – resting before and after, for example. But gardening can wait!

### Pace yourself

The activity diary can help you see where you're overdoing it, and in what ways you might need to make changes. Once you know what you can tolerate, you can start to plan activity around your capacity.

If you're just getting back into things after a period of reduced activity, remember to build up slowly. And remember – pacing means stopping BEFORE you feel like you need to. Don't wait until you hit the wall!

Aim to alternate activity and rest through the day, and throughout the week. It's easy to say, and quite hard to implement. But practice makes perfect!

### Balance

Balance means doing not too much, but also not too little. Of course, every day and every week will be different, but look for a general routine that you can manage and maintain.

As you re-emerge into normal life, this might mean starting small, and working into doing a bit more each week until it's a workable routine that you're happy with – remember that it's not

about catching up on every lost activity all at once.

Plan your day and your week to some degree, to enable balance – alternating activity and rest (more on that below). Also, try to find balance by alternating the way they use your body – e.g. sitting, standing, moving. The aim is not to be stuck in any one position for too long.

### Keeping doing – without overdoing

To help you find that balance, you can change the **duration** of some tasks. This can be especially true for tasks we enjoy.

For example, social engagements can be really tiring, and you might not feel it until later. The increased fatigue might make you want to say no next time – or, you might say yes and then end up overdoing it again.

How about shorter social engagements? You could try something like this: *"I'd love to have lunch, but can we make it coffee?"* or *"I'd love to see everyone, but I'll skip the movie and just come for dinner"*.

Hobbies and interests can get put aside too – maybe they're physically tiring, or maybe we don't feel we have time. But rather than all or nothing, try doing a bit at a time. It helps to schedule activities, so you can prioritise the things you love doing among all the things you really need to get done.

### Planning and scheduling

Time	Activity	Duration	Energy
0800-0900	<b>Breakfast</b>	30 min	6/10
	<b>Shower + dress</b>	30 min	5/10
0900-1000	<b>Phone with friend</b>	35 min	6/10
	<b>Gardening</b>	25 min	4/10
1000-1100	<b>Cup of tea, check emails</b>	30 min	5/10
	<b>Start lunch prep</b>	15 min	5/10
	<b>Sit and read paper</b>	15 min	6/10
1100-1200	<b>Put a load of washing on</b>	10 min	5/10
	<b>Continue reading paper (write, draw, puzzle...)</b>	15 min	6/10
	<b>Continue lunch prep</b>	15 min	5/10
	<b>Eat lunch</b>	20 min	5/10
1200-1300	<b>Read book after lunch</b>	30 min	6/10
	<b>Hang washing</b>	20 min	5/10
1300-1400	<i>And so on...</i>	60 min	0/10

Above is an example of achieving activity balance through planning and scheduling.



## Emerging Out Of Lockdown *(cont'd from P 11)*

Remember, everyone's tolerances are different – this one is based on the imaginary person from before. They've recognised that they were overdoing it with the gardening and falling into a boom-bust pattern, so they're now trying to pace and balance.

That doesn't mean they stopped gardening. This person loves gardening, so they want to continue doing it – but they're doing less today, and spacing it out across the week.

The restful activities (in **green**) can be somewhat productive as well – just using your body differently. And you can balance mental activities with physical ones, and also with total rest. Some people need an afternoon nap, and that's ok. It's about learning what you need and incorporating that into your routine.

And for the less meticulous planner, here's a more basic activity plan:

	MONDAY	TUESDAY	WEDNESDAY
MORNING	VACUUM 30 min  RESTFUL ACTIVITY  MAKE LUNCH	LIGHT GARDENING 30 min  RESTFUL ACTIVITY  MAKE LUNCH	VACUUM 30 min  RESTFUL ACTIVITY  MAKE LUNCH
AFTERNOON	EAT LUNCH, READ  OUT WITH FRIEND  RESTFUL ACTIVITY	EAT LUNCH, READ  GROCERY SHOP (split across two trips)  RESTFUL ACTIVITY	EAT LUNCH, READ  HANG WASHING  RESTFUL ACTIVITY
EVENING	PAINTING 45 min  RESTFUL ACTIVITY  MAKE DINNER  EAT DINNER, TV	GENTLE WALK  RESTFUL ACTIVITY  MAKE DINNER  EAT DINNER, TV	REST BEFORE GOING OUT  DINNER WITH FRIENDS  BED

This person is still balancing activity and rest, but not planning it all to the minute. Still, you'll see it generally alternates between something active and something restful. Remember, it's about whatever works best for you.

Also, note that on Wednesday afternoon they do a bit more rest than usual – you can see two **green activities** in a row – because they're going out for dinner with friends and they know that will be a **fatiguing activity**. But it's a priority for them, so they're working it out as best they can.

### Adapting everyday tasks

Here are a few more suggestions for making everyday changes to everyday tasks, in order to save your energy for the things that are important to you. This is by no means an exhaustive list!

Where you can, use **assistive technology** to save energy and make things easier. This can include:

- Shower chair and rails to make showering easier and safer
- A scooter or wheelchair so you can get out and about more without overdoing it
- Orthotic braces to preserve muscles and energy when you're walking
- Electric lift recliner or higher chairs to reduce effort in your legs
- Raised garden beds to avoid bending
- Laundry and/or kitchen trolley to carry things around the house, groceries from the car, etc.

Consider other **gadgets** that might help:

- Robot vacuum
- Slow cooker, rice cooker etc
- Steam mop
- Self-propelled lawn mower

**Sit where you can;** this will save your energy and limit prolonged standing. Tasks you might be able to do sitting down can include:

- Chopping vegetables
- Showering (on a proper shower chair)
- Ironing
- Folding laundry

**Avoid overdoing** tasks; keep it simple! Take cooking for example – you can cook simpler meals, and even freeze leftovers to save cooking on busy days.

**Get help if you need it!** Don't forget to accept those offers of help, or arrange services if you need them. The idea is to save your energy for the things you love doing!

### Any lasting changes?

Can you think of anything that changed during lockdown or restrictions that you might consider keeping? Are you an online shopper now? Or could you occasionally do virtual social catch-ups still, to continue to see friends but without having to go out all the time?

As we start to emerge back into the 'real world', now is a really good time to think about changes we want to continue.

### In summary

- Don't expect to just return to 'normal' instantly
- Choose which things you want to do first
- Reassess so you know what you can tolerate
- Pace yourself and build up
- Develop a sustainable routine
- Prioritise what you really want to do – cut back on other things, or accept help (or use gadgets)

So what will you prioritise as you step into the "new normal"? 🌟

## Forgotten After A Cyclone

**Ed Note:** Although the following incident occurred years ago, the recent weather affecting Australia's east coast could see similar situations occurring now. Please remember to check on your neighbours.

**By Inga Stünzner**

**Source:** [ABC Capricornia](#) – 3 February 2022

### **Robynne Clifton was stuck in her wheelchair for four days and forgotten after a cyclone**

Even though Cyclone Marcia was seven years ago, the experience of being left alone still haunts Robynne Clifton. (ABC Capricornia: Inga Stünzner)

Robynne Clifton's voice breaks when she describes her ordeal of being forgotten in the aftermath of a cyclone. It's an experience she doesn't want anyone else living with a disability to ever go through.

#### **Key points:**

- Robynne Clifton was stuck in her wheelchair, with no food, water or access to her bathroom after Cyclone Marcia
- Researchers develop a suite of tools to assist people with disability to make an emergency plan
- Australian Local Government Association says vulnerable people will fall through the cracks unless there is more federal funding for disaster mitigation

*"I was stuck in my lounge room for four days, with no food, no water and no way of getting to the bathroom," Ms Clifton said. "It was devastating. I just wanted to forget about living."*

Cyclone Marcia hit the central Queensland coast as a Category 5 storm on February 22, 2015, leaving a trail of destruction. The city was left without telephone connections and electricity for eight days.

For Ms Clifton, who has post-polio syndrome, the ordeal is still raw. She has been relying on her wheelchair since 2013, soon after her husband passed away. During the emergency, no one came to check on her.

*"I thought, how could anybody be so cruel," she said.*

In the lead up to the cyclone, Ms Clifton's carer told her to relocate to the local evacuation centre, which would keep her safe.

However, Ms Clifton was told by the centre's staff that they did not have the experience to



*Robynne Clifton says it is important for neighbours and the community to have empathy and kindness. (ABC Capricornia: Inga Stünzner)*

move her from her wheelchair and lower her into a bed. So she returned home and sat out the cyclone in her bathroom. *"It was very scary."*

Ms Clifton's one link to the outside world, a medical alert system, relied on power and then a battery, which ran out.

After four days and no sign of anyone coming to check on her, Ms Clifton said she called the ambulance for help.

The paramedics took her to hospital, but a nurse turned her away because she was not injured or sick. Her ordeal did not stop there.

When the power returned and Ms Clifton was able to power up her wheelchair, she travelled five blocks to a centre distributing water.

She was turned away because she did not live in that local government area; she lived just outside its border.

#### **Being forgotten too common**

Unfortunately, Ms Clifton's experience is not an isolated one.

Associate Professor Michelle Villeneuve, who leads the Disability-Inclusive Development work stream at the Centre for Disability Research and Policy at the University of Sydney, has come across hundreds of similar stories.

## Forgotten After A Cyclone *(cont'd from P 13)*

Dr Villeneuve said there had been situations where people with disability were left without their support services for up to 13 days.

*"One of the common themes that resonates over and over was this idea that nobody came, nobody checked on me," she said.*

*"When floodwaters are rising and people are found in their homes, up to their armpits in water, and only then neighbours recognised the risk and got emergency services in."*

Dr Villeneuve said people with disability, historically, had not been included in any emergency planning processes and that put them at greater disaster risk.

*"It means we don't know what their support needs are in emergency situations."*

As a result, Dr Villeneuve and her team developed a suite of tools that are accessible at [collaborating4inclusion.org](http://collaborating4inclusion.org) that put the person with disability in the driving seat to develop a disaster management plan with their carers and emergency personnel.

*"We actually have the first tool internationally where people with disability can self-assess their support needs, develop a clear understanding not only for themselves but can then communicate with their support network."*

### Falling through the cracks

Australian Local Government Association president Linda Scott welcomed the research and the program.

*"We know that local governments are the closest level of government to our communities and best equipped to deliver this kind of individual care," Ms Scott said.*

However, she said local governments were buckling under the increase in natural disasters due to climate change along with the continuous federal and state cuts to their budgets.

*"That is why, in the forthcoming federal election, we're advocating for a targeted disaster mitigation program of \$200 million per year over four years to support local governments to respond and help communities to recover and build resilience against future natural disasters."*

### Community kindness

Ms Clifton, who used to jump off stages during her days as an entertainer, now has her own disaster preparedness plan. But what is most important, however, she says are neighbours and a community.

*"If you have somebody who is vulnerable living in your area, what is wrong in knocking on their door and saying hi?," Ms Clifton said. "I think a lot of people need to a little more empathy."* 🌟

## Physio's Listed On Painaustralia's Directory

Painaustralia is expanding their [National Pain Services Directory](#) to include listings of allied health professionals. The first profession we are starting with are qualified physiotherapists with specialised training or qualifications in the area of pain.

Physiotherapists play an important role in the treatment, prevention and rehabilitation of individuals who experience chronic pain. Adding physiotherapists to our Directory will benefit consumers who are seeking access to allied health professionals to help with their chronic pain.

Since its launch in 2019 by Federal Health Minister, the Hon Greg Hunt MP, the Directory has become a valuable 'go to' tool for people living with chronic pain, GPs, other health professionals and consumers looking for a local pain specialist or clinic.

The Directory is updated continuously and features:

- State and territory locations.
- Highly sensitive and accurate geographical locations via the use of 'use my location' button which enables consumers to locate services close to work or home, via a list of services or via the map.
- Specific pain conditions or services which include back pain, pelvic pain, shoulder pain, pain psychologists, allied health professional referrals and pain rehabilitation services.
- Private and public service providers and contact details.
- Whether a service offers paediatric support services.

For more information, contact Painaustralia at: [admin@painaustralia.org.au](mailto:admin@painaustralia.org.au) 🌟



## Neil Balnaves Dies Aged 77

by Jo Litson

***The former television executive and leading arts philanthropist has died in a boating accident, aged 77.***

Source: [limelightmagazine.com.au](http://limelightmagazine.com.au)

– 22 February, 2022

Born in Adelaide, the former television executive established the Balnaves Foundation in 2006, which has awarded more than \$20 million to arts organisations including the Ensemble Theatre, Bangarra Dance Theatre, the Biennale of Sydney, the Art Gallery of New South Wales and The Art Gallery of South Australia. It has also supported Belvoir's Aboriginal & Torres Strait Islander Fellowship and Sydney Dance Company's [New Breed program](#). The Balnaves Foundation now dispenses \$3 million annually to the arts.

Balnaves worked in the media industry for over 60 years, holding the position of Executive Chairman of the Southern Star Group, which he founded in 1988. He was the Chairman of Ardent Leisure Group, which runs Dreamworld on the Gold Coast and other theme parks, from 2003 until 2016. Other former directorships include Hanna-Barbara Australia, Southern Star Group and Southern Cross Broadcasting. Among many other positions, he was a Board Member of the Art Gallery of South Australia from 2013 to 2019, and prior to his death was a member of the Chairman's Council at Sydney Theatre Company. He was appointed an Officer of the Order of Australia (AO) in 2010 for his services to business and philanthropy.

In a tragic irony, Balnaves – **who survived polio** – began working as a philanthropist having had an epiphany following a boating accident in 2002 that nearly killed him.

Tributes are flowing from the arts community. Mark Kilmurry, Artistic Director of the Ensemble Theatre, said in a statement: *"Neil Balnaves, through the Balnaves Foundation, was not only a major sponsor of Ensemble Theatre but he became a great friend and supporter."*

*"For more than six years, Neil, with his wife Diane and son Hamish, provided the most generous financial support and helped the Ensemble to evolve to where we are now."*

*"Neil had a vision to create a better Australia through education, medicine and the arts, especially First Nations artists, and was never afraid to stand up for what he believed in."*

*"He was a champion for the creative community, not just with his philanthropy but his personal passion for the arts. We will miss his generous and fearless spirit."*



Sydney Dance Company described Balnaves as one of its *"most passionate supporters"*, who took the time to join the company in New York when it performed there in 2017. In a statement, SDC said, *"Neil's boundless commitment to nurturing the future of Australian contemporary choreography has been demonstrated through the visionary support of The Balnaves Foundation for New Breed, Sydney Dance Company's annual season of emerging choreographic talent."*

*"Since the inaugural year of the partnership in 2014, Neil's enthusiasm for contemporary dance has been tangible and infectious; his interest in and curiosity for the shock of the new, his profound understanding of the environment required to foster creative talent and his belief in [Artistic Director Rafael Bonachela's] artistic vision for Sydney Dance Company have been appreciated by us all."*

*"Through his philanthropy, Neil has made a transformational difference to numerous arts, indigenous and medical charities across Australia. There are few like him and he will be sorely missed by us all."*

Balnaves was a member of the Sydney Theatre Company Chairman's Council since its inception by David Gonski in 2012, and he donated consistently every year. Ian Narev, the current Chairman of STC, said, *"All of us at STC were shocked to hear the sad news about Neil. Over many years he and his family and Foundation were strong supporters of STC's people and our art. And we were just one of many arts companies to benefit from this generosity. We send our deepest sympathies to the Balnaves family. He will be missed at the theatre."*

Bangarra Dance Theatre expressed its deep sadness at the loss of Balnaves, saying: *"Neil was a giant."*

## Neil Balnaves Dies Aged 77 (cont'd from P 15)

*He was profoundly passionate about making change, raising the profile of philanthropy in Australia, and leading by example. The Balnaves Foundation have generously supported Bangarra's Community Nights since 2017. Through their generosity we have provided subsidised ticketing to over 10,000 Aboriginal and Torres Strait Islander Community members nation-wide. Neil's legacy as a great advocate for the Arts and his deep commitment to working with First Nations People will be felt for many years to come."*

A fortuitous meeting with Balnaves in 2010 led to the establishment of an Indigenous playwright's award as well as a multi-year commitment to support Indigenous-led productions at Belvoir. Nakkiah Lui became the inaugural winner of The Balnaves Indigenous Playwright's Award in 2012. Subsequent winners include Leah Purcell, Ursula Yovich, Katie Beckett, Megan Wilding and Jada Alberts.

In 2019 the Award evolved into a Fellowship and was opened up to directors or writer/directors. The inaugural Fellow was Kodie Bedford, whose comedy *Cursed!* was presented in Belvoir's 2020 season. Subsequent recipients include Nathan Maynard, writer of the recently acclaimed play *At What Cost?*, Jorjia Gillis and current fellow *Thomas Weatherall*.

Belvoir said it was greatly saddened by the

tragic death of Balnaves, describing him as "an extraordinary person who had boundless energy and enthusiasm. Importantly he believed in the power of storytelling to Indigenous culture. Through stories we can learn and understand."

Artistic Director Eamon Flack described The Balnaves Fellowship as "a great way to make change, to give First Nations artists more autonomy, more artistic support, and more of a voice. It's one small part of the big national job of truth-telling, and we see this Fellowship as a key to Belvoir's role in that. Neil and The Balnaves Foundation have been instrumental in ensuring Indigenous theatre is not just created but also seen. With their support, Indigenous-led productions at Belvoir have included *The Drover's Wife* (now a major movie), *My Urrwai*, *Brothers Wreck*, *Barbara and the Camp Dogs*, *Which Way Home* and *Beautiful One Day*."

Chair of Belvoir, Sam Meers, said that "Neil has left an enormous legacy, not only to Belvoir, but to Australia's arts industry. His passionate advocacy for the arts, and for cultural philanthropy, was contagious and inspiring. We will miss his dynamism, passion and unflinching intelligence."

Balnaves is survived by his wife Diane, son Hamish and daughter Victoria. Sadly, their eldest daughter Alexandra died in 2019 following a long illness. 🌟

## Pandemics Disable People

By Laura Spinney

***Influenza, polio and more have shown that infections can change lives even decades later. Why the complacency over possible long-term effects of COVID-19?***

Source: [www.nature.com](https://www.nature.com) — 16 February 2022

When Ashley Shew turned up for an appointment at a medical centre in spring 2020, a member of staff told her she could remove her mask because only people with pre-existing conditions were vulnerable to COVID-19. Shew was surprised. "A hard-of-hearing amputee battered by chemotherapy and more", as she describes herself, she is a regular at the centre — the appointment that day concerned her prosthetic leg. Who, she wondered, did the staff member think counted as a person with pre-existing conditions?

The invisibility of disability is not new, says Shew, a 38-year-old philosopher who explores the intersection of technology and disability at Virginia Polytechnic Institute and State University in Blacksburg.



*Virginia Lewis Hall's post-polio syndrome makes breathing difficult; the newspaper clipping shows her in an 'iron lung' respirator as a child.*  
Credit: Tom Smart/New York Times/Redux/eyevine

## Pandemics Disable People (cont'd from P 16)

*"But it is particularly deadly that we don't frame COVID-19 as a disability issue," she says. "Even linguistically we're pointed away from it. 'Pre-existing conditions' is a way of not saying 'disability'."*

From the beginning of this pandemic, people with disabilities understood that the disease would target them and would swell their ranks. Disability historians knew that there was a penumbra of ill health to previous mass-death events. Health economists warned that, as with tuberculosis, HIV and other diseases, morbidity would stalk mortality. Too many others have clung stubbornly to a belief that COVID-19 is something from which a minority of people die, and that most bounce back quickly and intact, with only their immune system updated. The longer the pandemic drags on, the harder it is to maintain that fiction.

Two years in, the debilitating tail of the pandemic has revealed itself in the form of tens of millions of people living with long COVID<sup>1</sup>. It is high time to ask whether attitudes to disability will change as a result. Will society grasp that the body can be altered for a long period — even permanently — by infectious disease, just as it seems to have accepted that the body politic will never be the same again? And will it make the necessary accommodations?

These questions have been asked before.

### Long influenza

Consider the 'mother of all pandemics' — the 1918 Spanish influenza outbreak. Even in the 1920s, scientists understood that this flu had neurological and other effects. The most notorious and debated of those — still — is the overlapping pandemic of encephalitis lethargica (EL) or 'sleepy sickness'. Eighty per cent of EL survivors went on to develop a Parkinson's-like disease<sup>2</sup>. According to cell biologist Richard Smeyne at the Jefferson Hospital for Neuroscience in Philadelphia, Pennsylvania, it has never been proved biologically that flu caused both EL and this post-encephalitic parkinsonism — at least not in the sense of catching the virus in flagrante in the brain tissue of people who had died. Yet the statistical case for it seems strong<sup>2</sup>.

The neurological tails of two subsequent flu pandemics, in 1957 and 1968, were less pronounced, but both were followed by rises in cases of encephalitis (brain inflammation), among other conditions<sup>2</sup>. Once again, researchers failed to demonstrate a clear causal link with an earlier flu infection, but it has since been established that the flu virus can infect the brain and trigger inflammation there and elsewhere in the body. Clinicians see this after every flu season, in a wave of strokes and heart

attacks predominantly among older people<sup>3</sup>. And flu can cause encephalitis in children. It's rare, but it can kill, and those who survive can be left with long-term brain damage<sup>2</sup>.

Flu is by no means the only infectious disease with long-term effects. For old foes such as measles and hepatitis, complications are well documented — such as the progressive neurological disorder subacute sclerosing panencephalitis and chronic liver disease, respectively. And researchers might even have good insight into the mechanisms that cause them.

With new diseases, or new variations on old diseases, long-range effects take time to be characterized. It took decades for researchers to prove a hunch that infection with the Epstein-Barr virus is a trigger for multiple sclerosis<sup>4</sup>, for example. There are reasons it's not always easy to connect late-developing symptoms to the acute form of the disease, and identify a common cause.

Take Ebola. Ever since the outbreak in West Africa in 2014, researchers have recognized a post-Ebola syndrome that affects the heart, brain, eyes and joints<sup>5</sup>. How the Ebola virus causes symptoms across so many organs is not yet clear. Studying the problem is complicated by the fact that, because Ebola is so deadly — killing around half those it infects — survivors experience significant social stigma.

Stigma can draw a veil of silence around a disease's chronic effects, with the result that they don't filter into the public consciousness. Jeanne Billieux, an infectious-diseases clinician at the US National Institute of Neurological Disorders and Stroke in Rockville, Maryland, has been following survivors of Ebola in Liberia since 2015. Many of them were expelled from their villages, she says: *"They're getting better over time, but a significant proportion are still symptomatic."*

### Post-polio syndrome

Before virologist Jonas Salk's polio vaccine was approved in 1955, the terrifying polio epidemics that swept North America and Europe each summer scarred the collective imagination. That mobilized support for the US non-profit organization March of Dimes, which helped to fund the vaccine. After 1955, there was a sense that the problem had been solved.

When, decades later, a proportion of the survivors of those epidemics relapsed — estimates vary between 20% and 85%<sup>6</sup> — their condition failed to elicit the same level of concern.

As encroaching respiratory and motor difficulties forced people back into dependence



## Pandemics Disable People (cont'd from P 17)

on aids for breathing and mobility, their priorities were re-ordered as radically as it's possible to imagine. Medical anthropologist and historian Joseph Kaufert at the University of Manitoba in Winnipeg, Canada, interviewed people with post-polio syndrome in the 1980s and 1990s<sup>7</sup>. *"When I was up in the wheelchair it was just a matter of trying to breathe," one man told him. "That was a day's work."*

For Kaufert, the invisibility of these individuals owes much to a failure of collective memory. As their hard-won autonomy seeped away, they often reached out to the respiratory physicians who had treated them initially. But many had retired, and younger clinicians showed less interest. *"It was really hard to build a career on an illness from the past,"* Kaufert says.

In the 1980s, medical researcher Albert Sabin, who developed the polio vaccine that replaced Salk's, drew attention to post-polio syndrome, and March of Dimes took up the cause. It quickly became clear that there would be no silver bullet, no equivalent of the vaccine. The solution would involve mixing and matching therapies to suit each individual. That was a harder sell to the money-giving public.

Looking back over the twentieth century, it's impossible to ignore the scarring effects of infectious disease. Yet when a new virus emerged in late 2019, even the best-resourced nations failed to anticipate its long-term impact.

### The long haul

Long COVID is the latest reminder that epidemics have long tails – biologically, as well as psychologically, economically and socially. Since the persistent effects of COVID-19 were recognized 6 months into the pandemic, up to 200 symptoms have been reported<sup>8</sup> in 10 organ systems<sup>9</sup>, including the skin, brain<sup>10</sup>, heart<sup>11</sup> and gut. The recurring core<sup>12</sup> of these comprises loss of mobility, lung abnormalities, fatigue and cognitive and mental-health problems. But it's clear that long COVID is a catch-all term for a panoply of post-viral syndromes. Consequently, there is no simple test for it. Diagnosis is based on clinical symptoms, past infection with COVID-19 and the lack of an obvious alternative cause.

There was a tendency among medics to play down long COVID to begin with. Now, thanks in large part to the voice that 'long-haulers' found as they came together in a global online community that includes health-care workers, long COVID is the subject of large grants, research projects and a few specialist clinics, including for children.

Yet it continues to be overlooked by decision makers, who still present the costs and benefits

of COVID-19 containment in terms of data on cases, hospitalizations and deaths alone. This means that in many countries, a burden of future disability is being created that could have been prevented, or reduced.

In May 2021, health economists at the London School of Hygiene & Tropical Medicine estimated that COVID-induced disability might account for roughly 30% of the pandemic's overall health burden<sup>13</sup>. Theirs was an early, necessarily limited attempt at quantification. It excluded mental illness, for example. More recent estimates, made in the light of accumulating but still partial knowledge about long COVID, indicate that disability is likely to account for the lion's share of COVID-19's burden, and might disproportionately affect women, especially those who were infected young<sup>14</sup>.

These estimates remain crude, not least because too little is known about COVID-19's long-term effects on children. And they do not capture the impact of the predicted wave of disability on carers. Numbers will be refined as time goes on, and as data come in from ongoing studies, such as COVID-CNS (led by the University of Liverpool, UK, and King's College London) and STIMULATE-ICP (led by University College London).

Meanwhile, work proceeds on trying to understand how the coronavirus SARS-CoV-2 triggers long-term effects. Just how it damages the central nervous system is a matter of heated debate, for example<sup>15-19</sup>. One theory is that SARS-CoV-2 prompts a fleeting immune response that primes the brain for a later insult – genetic or environmental. If such a model applies more broadly, it might explain why it has been so hard to demonstrate a direct biological link<sup>15</sup> between viral infection and neurological disease, says Smeyne. It could also make it fiendishly difficult to predict who will succumb later. *"It's like, spin the wheel,"* he says.

It could even turn the idea of pre-existing conditions on its head. Does transient infection itself create a vulnerability which, sometime later, might or might not translate into an epidemic of disability?

### Disability rights

In the past, awareness of the disability that contagion brings in its wake has translated into meaningful change. In the United States, for example, polio survivors Judith Heumann and Ed Roberts emerged as leaders of the disability-rights movement. They were influential in pushing through legislation intended to improve life for all people with disabilities, including the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

## Pandemics Disable People (cont'd from P 18)

One of long-haulers' clearest demands has yet to be reflected on national or international data dashboards. Namely that the tsunami of COVID-induced disability is acknowledged in pandemic policymaking, not just in scientific grants, papers and clinics. *"There is a strange disconnect whereby health ministers are now talking about the gravity of long COVID, but it features nowhere in the considerations on which they base their pandemic policy,"* says Nisreen Alwan, a public-health specialist at the University of Southampton, UK, who is herself recovering from long COVID.

And many long-haulers have found common cause with clinically vulnerable people in calling out the ableism and disablism (see [go.nature.com/336rjwc](https://go.nature.com/336rjwc)) of policies that fail to keep COVID-19 case numbers low. Rampant spread not only raises the risk of more troublesome variants evolving, it also sets more people up for long-term health problems — especially those who are already marginalized — and it limits the lives of millions for whom vaccines are unavailable or ineffective.

Public health has always privileged the acute over the chronic, but this is about more than discounting the future. It's about duelling models of disability — the medical and the social. When will it be safe for the adult with severe asthma to return to in-person work? How is the thriving child with an organ transplant to get educated if there's no vaccine for her, no masks or tests for her classmates, no notifying

her parents when there's a case in class, and public messaging that runaway infection among children is fine?

The extent to which such conditions are disabling is largely determined by society's willingness to adapt, notes historian Catherine Kudlick, who directs the Paul K. Longmore Institute on Disability at San Francisco State University in California. She says: *"Like disability in general, the pandemic causes you to re-evaluate your priorities and say, 'OK, what really matters?'"*

Shew points out that, during the lockdowns triggered by the present pandemic, accommodations that disabled people had long campaigned for — remote working, and flexibility in working hours, communication format and metrics of productivity — were universally adopted. She worries that they'll be dropped in some futile quest to return to a pre-pandemic 'normal'. Yet she also draws hope from Heumann and Roberts.

If polio survivors could drive social change in the past century, perhaps COVID-19 survivors will in this one — making all disability more visible. *"If it weren't built on suffering and death,"* Shew says, *"it would be an exciting time to be thinking about disability rights."*

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**Read full article and References [here](#).**

## Joni Mitchell And Neil Young Pull Music From Spotify

**By Brenton Blanchet**

**Source:** [www.complex.com](https://www.complex.com) – 30 January 2022

[Joni Mitchell](#) never lies—and this time she's certainly not holding back.

The legendary musician announced on Friday night that her extensive music catalog, including iconic tracks like *"Big Yellow Taxi,"* will no longer be available on [Spotify](#) following her decision to remove it.

Her move comes after her [friend Neil Young did the same](#), citing vaccine misinformation being spread on the [Joe Rogan Experience](#) podcast—which has an exclusive [\\$100 million licensing deal](#) with the company. **Both Young and Mitchell are survivors of polio**, which they contracted in the early 1950s before a vaccine became available shortly after.

*"I've decided to remove all my music from Spotify," Mitchell wrote via a [website statement](#). "Irresponsible people are spreading lies that are*

*costing people their lives. I stand in solidarity with Neil Young and the global scientific and medical communities on this issue."*

*"I am doing this because Spotify is spreading fake information about vaccines – potentially causing death to those who believe the disinformation being spread by them",* Young wrote in his own letter to his manager Frank Girona and Warner Bros co-chairman and Chief Operating Officer Tom Corson. *"Please act on this immediately today and keep me informed of the time schedule."*

Spotify later agreed to pull Young's music from the platform, per his request.

*"We want all the world's music and audio content to be available to Spotify users. With that comes great responsibility in balancing both safety for listeners and freedom for creators,"* a spokesperson [told](#) *The Hollywood Reporter*. *"We have detailed content policies in place and we've removed over 20,000 podcast episodes related to COVID since the start of the pandemic."*

## Esther Missed Out On The Polio Vaccine

***Her children won't miss their COVID jabs.***

**By Steven Trask**

**Source:** [www.sbs.com.au](http://www.sbs.com.au) – 30 January 2022

Polio survivors in Australia share their views on the importance of getting vaccinated against COVID-19, particularly as schools prepare to welcome children back.

Esther Simbi never had the chance to get vaccinated against the debilitating and sometimes fatal polio virus.

*"When I was born in South Sudan, at the time there was no vaccination, and many people, including me, contracted polio," she said. "I was four years old in a village called Lomura. There was no protection, and I've been living with a disability since – living with the weaknesses of my leg and lower back."*

Esther missed out on one crucial vaccine, but now in South Australia and raising two young daughters – aged 11 and six – she is determined to get them vaccinated against COVID-19.

*"The reason why I want my children to be vaccinated is for protection," she said. "Some people are dying when they contract COVID, especially if they have underlying health issues. And my younger one, she was born with congenital lung disease."*

Polio is caused by a highly infectious virus that can impair the body's central nervous system, disrupting muscle development and, in some cases, causing paralysis.

*"My muscles weaken every year. Now I found I use the wheelchair more than even five years ago," said Esther, who is a published author as well as a project officer for a disabilities support organisation. "My left leg is completely weak, my physiotherapist wondered how I even walked."*

The first polio vaccine was developed by American virologist Jonas Salk in the 1950s. Medical researcher Albert Sabin invented an oral vaccine in 1955.

Today, in large part because of child vaccination, polio has been eradicated in all but two countries; Pakistan and Afghanistan.

Australia experienced its last major polio outbreak in the 1950s. Shirley Glance contracted polio during that outbreak – she was just 14 months old.

*"I was just starting to walk and my mother noticed that I kept falling over," said Shirley, who is the president of Post Polio Victoria. "I was diagnosed with polio and I've lived with it since. Children were taken away from families, they were isolated because they didn't know how far*



*Author and advocate Esther Simbi with her two young daughters in Adelaide.*  
Source: Jo-Anna Robinson/NDIS

*it would spread. I'm not complaining about the life I've had, but my life would've been different had I had the polio vaccine."*

Robyn Abrahams, a former nurse and management consultant who is also based in Victoria, contracted polio in 1953 as a three-year-old.

*"I remember being tied to the bed by all fours. They put us in big long splints to keep us straight and rigid," she said. "If I was prime minister for a day, God help us all; one of the things would be there is no discussion about vaccination of any type," she added. "Be it from measles to coronavirus, you will all be vaccinated because our health system can't afford you not to be."*

On 10 January, Australia started COVID-19 vaccinations for children aged between 5 and 11. While many parents rushed to get their children vaccinated, the move was also met with hesitation.

Perth-based infectious disease paediatrician Dr Asha Bowen said Australia had a world-class regime for monitoring the vaccine rollout among children. Vaccines were also crucial in getting children back to school, she added.

*"From a parent perspective, I'm actually really pleased that we had both the clinical trial as well as that safety surveillance data before we rolled out our program. It gives me great confidence for my children in vaccinating them and it also gives me great confidence as a paediatrician that this is a good program to recommend to families in Australia. I'm also really, really supportive of our kids being in school, face to face learning, whenever they possibly can be, and I think a vaccine program adds that extra layer of protection."*



## WHO Says Wild Polio Remains A Risk

**By Reuters – SBS**

**Source:** [www.sbs.com.au](http://www.sbs.com.au) – 20 February 2022

The detection of wild polio in Malawi has sparked a warning from the World Health Organization that the virus poses a risk to all countries.

Malawi has declared a polio outbreak after a case was detected in a young child in the capital Lilongwe, the first case of wild poliovirus in Africa in more than five years, the World Health Organization (WHO) said.

Laboratory analysis showed the strain detected in Malawi was linked to one that has been circulating in Pakistan, where it is still endemic, the WHO said in a statement.

*"As an imported case from Pakistan, this detection does not affect the African region's wild poliovirus-free certification status,"* the WHO said.

The Global Polio Eradication Initiative said the case in Malawi was in a three-year-old girl who experienced the onset of paralysis in November last year.

Sequencing of the virus conducted in February by South Africa's National Institute for Communicable Diseases and the US Centers for Disease Control and Prevention confirmed it as type 1 wild poliovirus (WPV1).

*"Detection of WPV1 outside the world's two remaining endemic countries, Pakistan and Afghanistan, is a serious concern and underscores the importance of prioritising polio immunisation activities,"* the Global Polio Eradication Initiative said.

The WHO said the African continent was able to respond rapidly because of a high level of surveillance.

*"The last case of wild poliovirus in Africa was identified in northern Nigeria in 2016 and globally there were only five cases in 2021. Any case of wild poliovirus is a significant event and we will mobilise all resources to support the country's response,"* said Modjirom Ndoutabe, polio coordinator in the WHO's regional office for Africa.

Polio is a highly infectious disease that invades the nervous system and can cause total paralysis within hours. While there is no cure, it can be prevented by vaccine, the WHO said.

*"The strain of poliovirus detected (in Malawi) is a close match to a strain last detected in a child with paralysis in the (Pakistani) province of Sindh in October 2019,"* said Hamid Jaffery, Director, Polio Eradication, WHO Eastern Mediterranean Region.

*"Until we stop transmission of polio in Afghanistan and Pakistan, the world remains at risk,"* he told Reuters.

Pakistan is among countries where it is recommended international travellers have polio vaccination certificates.

Pakistan's health minister Faisal Sultan told Reuters the genetic cluster had disappeared from the country since around 2019.

*"Further analysis may reveal its hiding place since then – perhaps somewhere in the world where there are pockets of 'immunity gap' and non-existent environmental surveillance,"* he said. 🌍



## Ukraine Conflict Could Spark Surges Of Diseases

By Loveday Morris and Dan Diamond

Source: [www.washingtonpost.com](http://www.washingtonpost.com)  
— 2 March 2022

LVIV, Ukraine — At the main train station in this western Ukrainian city, where the internally displaced jostle to get on trains to Poland or change for other destinations in Europe, few among the heaving crowd wore masks. As night fell, hundreds bedded down across crowded stone floors or curled up on the stairs, inhaling thick, muggy air.

For these Ukrainians, the focus is escaping the Russian invasion bearing down on their country — not on dodging diseases such as covid-19.

But as more than [half a million people have fled Ukraine to neighboring countries](#), global health officials fear that Russia's invasion of Ukraine will be the latest reminder of a grim lesson — that war and disease are close companions, and the humanitarian and refugee crises now unfolding in Eastern Europe will lead to long-lasting health consequences, exacerbated by the [coronavirus](#) pandemic.

As Russia's military campaign accelerates, Ukraine's hospitals are running out of critical medical supplies as travel is increasingly choked off by the conflict. The country's health workers and patients are relocating to makeshift shelters, seeking to escape explosions. Meanwhile, officials at the World Health Organization, United Nations, U.S. State Department and other organizations warn of rising civilian casualties and new pressures on the region's fragile health-care systems.

"What we're dealing with now in Ukraine is a double crisis," said Máire Connolly, a global health professor at the National University of Ireland Galway who has [studied](#) the link between conflict and disease. In an interview, Connolly said she was worried not just about threats from the coronavirus pandemic but also those from Ukraine's **polio outbreak**, which global experts had sought to quell for months. She also said she fears the potential resurgence of tuberculosis during the current conflict.

"As we've seen in wars over the years, viruses and bacteria are happy to exploit those situations where human beings are put under pressure," Connolly added, citing how refugees fleeing armed conflict can end up in overcrowded conditions and without sufficient water, food and sanitation. "These factors increase the risk of outbreaks among a population that are already dealing with the trauma of forced displacement."

While covid cases in Eastern Europe have plunged in recent weeks, experts such as Connolly say they're worried that the regional

conflict will trigger new spikes. Ukraine experienced some of the world's highest rates of coronavirus late last year, and is flanked by countries with some of the lowest vaccination rates in Europe — raising the prospect that the movement of thousands if not millions of refugees could lead to surges of illness in neighboring countries.

"I am heartbroken and gravely concerned for the health of the people in Ukraine in the escalating crisis," Tedros Adhanom Ghebreyesus, director general of the WHO, said in a statement as the conflict began last week. The WHO leader also shared a [video](#) on Twitter of newborns in Ukraine being cared for in a makeshift bomb shelter, calling the images "beyond heartbreaking." On Sunday, he warned that Ukraine is now dealing with a dangerous shortage of oxygen supplies needed to treat covid and other conditions.

"The majority of hospitals could exhaust their oxygen reserves within the next 24 hours. Some have already run out," the WHO said in a statement. "This puts thousands of lives at risk."

U.S. officials, Ukraine's health minister and others have also accused Russian military forces of firing on the country's ambulances and hospitals, and experts remain concerned the conflict could [disturb radioactive waste](#) being stored at the Chernobyl nuclear plant, sparking additional health and environmental disasters.

Global humanitarian organizations have moved to shore up Ukraine's health safety net. The WHO, which began positioning additional medical supplies in Ukraine in November after Russian military forces began to mass on its borders, on Thursday made \$3.5 million available in additional emergency funding. The U.S. Agency for International Development deployed a disaster response team to nearby Poland, intended to help coordinate the regional humanitarian response, and along with the State Department, will provide nearly \$54 million in additional assistance. The White House also is [seeking \\$6.4 billion](#) for emergency aid to the region, much of which would go toward humanitarian assistance.

U.S. officials and outside experts say they're bracing for further shocks. "Despite the immense, multinational efforts to prepare for this scenario, we know that many Ukrainians will needlessly suffer at the hands of Russian aggression," USAID Administrator Samantha Power said in a statement on Friday.

Power, who [spent time](#) at the Poland-Ukraine border this weekend, said Monday that as many as 5 million refugees could flee Ukraine in coming weeks.

## Ukraine Conflict ... (cont'd from P 22)



*Reception center for Ukrainian refugees at the main railway station in Przemyśl, Poland, on Feb. 27. (Kasia Strek for The Washington Post)*

Humanitarian and health groups also had not anticipated an invasion from multiple directions; they expected it to be concentrated on the country's eastern border, where they had positioned emergency supplies in advance, said Simon Pánek, CEO of People in Need, a humanitarian organization working to deliver aid.

*"Until a few days before the war started, my colleagues and I didn't talk about the possibility that there would be a direct offensive on Kyiv from the north, for example," Pánek said in an interview from Prague, where he is based. "What we need most is safe transport to central and eastern Ukraine, but no one from outside can provide it," Pánek added, saying his group had sent five trucks filled with supplies on Sunday and had planned to send more aid on Tuesday.*

Meanwhile, the accelerating Russian military campaign has posed mounting challenges, with explosions across Ukraine's major cities and more military forces pouring into the country.

*A "health system cannot function during an active bombing campaign," Rachel Silverman, a policy fellow at the Center for Global Development, wrote in a series of text messages from Germany. "They must evacuate patients from hospitals, all routine services will be put on hold, many facilities will be damaged and health workers will flee."*

Russia's invasion of Ukraine also comes on the heels of a coronavirus outbreak that skyrocketed

late last year and [saw the region become a global hot spot](#). While Ukraine's case numbers have fallen sharply, public health experts say large movements of people could spark new infections in Eastern Europe, where vaccination rates trail countries to the west. Only one-third of Ukrainians have received at least one dose of a coronavirus vaccine, according to the University of Oxford's Our World in Data tracking project, compared with more than three-quarters of people in countries like France, Germany and Britain.

*"Covid is understandably not top of mind for anyone" during an armed conflict, Silverman wrote in a message. "But having people in crowded subways, with no real access to health services, is a terrible situation. Even the mildest covid cases can be very problematic if you have no place to isolate/get care, and/or if you need to flee on foot."*

Many Ukrainians are now seeking shelter in neighboring Poland, which has waived its standard coronavirus quarantine and testing requirements for those refugees.

Poland's health minister also announced free coronavirus vaccinations for Ukrainians on Friday.

But like Ukraine, Poland has had a severe covid outbreak in recent weeks, and officials say its health system is dealing with a significant workforce shortage that has sparked walkouts and [protests](#). About 59 percent of Poland's population has received at least one vaccine shot. Poland is set to lift many of its remaining coronavirus restrictions on Tuesday.

Jarno Habicht, the WHO's representative to Ukraine, told reporters that he was worried that the conflict would set back months of progress to vaccinate Ukrainians while escalating other regional health crises, such as the **polio outbreak**.

Russia's invasion "will have implications across the whole country," he said, adding that his team was rapidly pivoting to address a brand-new set of health challenges. "Our priorities have shifted to trauma care, ensure access to services, continuity of care, mental health and psychosocial support."

*Diamond reported from Washington. Max Bearak in Przemyśl, Poland, contributed to this report.* 🌐



