



The Duncan Foundation

A new national support service for people living with neuromuscular conditions.

Gordon Jackman - CEO

For Life.



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FOUNDATION

We currently support people living with:

- Late Effects of Polio
- Friedreich Ataxia
- Recently Diagnosed Parkinson's (aprox. 1 year)
- Dystonia

Our Goal is to empower people with neuromuscular conditions to live to their maximum physical potential

Our approach is to support self management with assessment, planning and follow up, getting the support needed.



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Aims of the Duncan Foundation

- To support or establish a number of clinics in New Zealand that have the capacity to assess people throughout the country who have or have had neurological conditions for the purpose of guiding rehabilitation and ongoing support.
- To develop a national network of affiliated clinicians and health professionals who can work with the clinics to provide the best possible multi-disciplined consultation teams.
- To develop and deliver educational resources so that general practitioners, clinicians, health professionals, and needs assessment and service coordination assessors have the information they need to properly understand those living with neurological conditions or the late effects of those conditions.

Aims of the Duncan Foundation



- To work with district health boards and public health organisations to integrate the clinics as far as possible with the public health system.

HealthPathways

- To work with other organisations which also support those with neuro muscular condition to:
 - a) explore opportunities for collaboration and
 - b) avoid duplication.
- To fund the treatment and or equipment needed for the ongoing rehabilitation and support people who have or have had neurological conditions.
- To develop and support on an ongoing basis, any other activities related to a neurological condition.



Late Effects of Polio Search

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3 results found containing all search terms.

Late Effects of Polio



Home



Neurology



Late Effects of Polio

Background

About late effects of polio

About late effects of polio

There may be about 8,000 paralytic polio survivors in New Zealand, 40,000 in Australia, and 100,000 in the UK. Accurate data are not available.¹

Polio was eradicated from NZ and Australia by 1961 and many of those affected are entering old age. Younger polio survivors may have been born overseas. Polio is still an active problem in Nigeria, Afghanistan, and Pakistan.


Most polio survivors experience a modest decline in function and muscle strength over many years, however other patients can experience a syndrome of either new or progressive symptoms (called "Late Effects of Polio") such as weakness, fatigue, muscle atrophy, and pain. These new or progressive symptoms often occur many years after the original illness. The new weakness always occurs in muscles previously affected by the disease, although this may have been so minor as to not be apparent. The cause is unclear and may be related to failure of the recovered nerve supply to muscles. Continuing viral activity, inflammation, and autoimmunity have been suggested.

Patients who were older when they suffered acute poliomyelitis and those severely affected with the greatest recovery develop the most severe late symptoms. Some patients who had the "polio flu" but apparently fully recovered, can have some late effects of polio.

Assessment


1. Consider alternative causes for symptoms, especially when there is no clear history of polio.
 - Be aware that false attribution of symptoms to polio is an issue.
 - Note that new focal symptoms at a different site may indicate a different diagnosis. Late effects of polio always occur in muscles originally affected, although the original effect may have been so minor as to not be apparent, making this challenging to determine.
2. History:
 - Ask about muscle weakness, wasting, pain, fatigue, respiratory or sleep symptoms, and assess [dysphagia](#), [speech difficulties](#), urinary symptoms, and [restless legs syndrome](#).
 - Establish the history of the original paralytic polio and compare this to the current symptoms.
 - Include sites affected, severity, recovery and surgical history.
 - Take note of progressive neurological symptoms.
3. Assess mental state and social functioning related to disability, including [fitness to drive](#).
4. Examination:
 - Check for focal neurological signs and musculoskeletal abnormalities. Weak muscles show lower motor neurone signs of wasting, fasciculation, and absent reflexes.
 - Measure body mass index (BMI).
5. Investigations are not usually required unless an alternative diagnosis is expected, in which case follow recommendations on the relevant pathway.
 - Electromyography (EMG) is usually arranged by neurologists.
 - If respiratory or sleep symptoms are present, consider arranging [spirometry](#) to look for hypoventilation.

Management



1. If the diagnosis is not clear or symptoms are rapidly progressive, request [non-acute neurology assessment](#). Most patients with late effects of polio are managed in general practice with allied health assistance.
2. Provide  [patient information](#).


Patient information

- Advise patients of the nature of the syndrome.
- Reassure that body areas not previously affected are unlikely to be severely affected in the future.


3. Provide [flu](#) and pneumococcal vaccination.
4. Manage patient symptoms:
 - [Pain](#) and [restless legs syndrome](#) – manage according to pathways.
 - Urinary symptoms and neurogenic bladder – manage according to Urinary Incontinence pathways.
 - [Sleep disordered breathing](#) – manage according to the pathway. If assessment suggests hypoventilation, especially with dyspnoea or sleep disturbance, request [non-acute respiratory assessment](#) for consideration of non-invasive support such as continuous positive airways pressure (CPAP) or bi-level positive airways pressure (BiPAP).
 - Swallowing and speech difficulties – request [adult speech language therapy assessment](#).
 - Gait disorders and need for orthotic devices, request [orthopaedic and musculoskeletal physiotherapy](#). A physiotherapy assessment of gait and mobility before surgical referral makes acceptance of the referral more likely.
 - Fatigue –  [manage fatigue levels](#) in daily life.

Manage fatigue levels



- Give [advice on pacing, rest, and exercise](#).
- Arrange low intensity supervised exercise avoiding [fatigue](#). This may assist with many symptoms, including fatigue.

5. Request physiotherapy assessment for low-intensity muscle strengthening, pacing, gait, and mobility through the  [Duncan Foundation](#).
6. Arrange support for patients with functional support needs (including advice on activities of daily living and [fitness to drive](#)) so that energy can be conserved for meaningful activity – request [community occupational therapy](#).
7. Manage mental state and social functioning according to long-term care of patients with long-term disorders.

Request

- Request [non-acute neurology assessment](#) if:
 - the diagnosis is in doubt.
 - symptoms are rapidly progressive.
- If assessment suggests hypoventilation, especially with dyspnoea or sleep disturbance, request [non-acute respiratory assessment](#) for consideration of non-invasive support such as CPAP or BiPAP.
- For swallowing and speech difficulties, request [adult speech language therapy assessment](#).
- For gait disorders and orthotic devices, request [orthopaedic and musculoskeletal physiotherapy](#).
- Request physiotherapy assessment for low-intensity muscle strengthening, pacing, gait, and mobility through the  [Duncan Foundation](#).

Duncan Foundation

- The [Duncan Foundation](#)  funds one physiotherapist assessment per patient with a physiotherapist experienced in the late effects of polio.
 - The physiotherapist will carry out a functional assessment and provide a report including recommendations back to the general practice.
 - [Register](#)  via the Duncan Foundation website.
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- For patients with functional support needs, (including advice on activities of daily living and fitness to drive), request [community occupational therapy](#).



[For health professionals](#)

Further information

- [British Polio Fellowship – Post Polio Syndrome](#)
- [Patient – Post-polio Syndrome](#)
- [Polio NSW – The Late Effects of Polio: Information for General Practitioners](#)



[For patients](#)

- [Duncan Foundation – Information Hub](#)
- [HealthInfo – Polio](#)
- [Polio NZ Inc – Resources for Polio People](#)



[Sources](#)

References

1. Jones KM, Balalla S, Theadom A, Jackman G, Feigin VL. [A systematic review of the worldwide prevalence of survivors of poliomyelitis reported in 31 studies](#). *BMJ Open*. 2017 Jul 09;7(7):e015470.

Duncan Foundation Polio Clinicians



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- Julie Rope - Vestibular and Neurological Senior Physiotherapist
National Clinical Lead Duncan Foundation
- Lillian Drummond - Senior Neurological Physiotherapist
Rope Neuro Rehabilitation www.ropeneurorehab.co.nz
Auckland
Mob. 021 753 276 Office: 09 623 8433
- Ruth Noakes - Principal Physiotherapist
Island Bay Physiotherapy www.islandbayphysio.co.nz
Wellington
Office 04 3838 700
- Jessie Snowden - Senior Physiotherapist and Director
On the Go Physio Ltd www.onthegophysio.co.nz
Christchurch
Mob: 021 030 9061 Ph: 0800 000 856
- Amelia Petherick - Neurorehabilitation Physiotherapist
Amelia Petherick Physiotherapy
Blenheim, Marlborough
Mob: 021 689 681

