



ABRN 142 977 053

POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

Dr John Tierney OAM, President Suite 119C, 89 High Street KEW Vic 3101
Email: office@polioaustralia.org.au PO Box 500 Kew East Vic 3102
www.polioaustralia.org.au Phone: 03 90167678 / Mobile: 0466 718 222

NUMBERS OF POLIO SURVIVORS LIVING IN AUSTRALIA

Position Paper

Polio Australia estimates that approximately 400,000 polio survivors are "*still here!*" in Australia and living with the Late Effects of Polio (LEoP). This estimate is an extrapolation based on known facts.

Although poliomyelitis (polio) became a notifiable disease in 1922, records were poorly maintained and many cases were either not reported at all, or misdiagnosed and reported as illnesses such as encephalitis, meningitis, or influenza. In some years (for example, the war years), and in some areas (for example, the Northern Territory), reporting was very patchy. In addition, many people who contracted poliomyelitis during the epidemics of the last century may be unaware of their infection, and there also remains a reluctance to admit to being a polio survivor due to the stigma associated with polio infection pre-vaccine.

In describing polio an NCIRS Fact Sheet¹ notes that "*Clinical manifestations of poliomyelitis can vary and they are categorised according to severity. A large majority (up to 95%) of polio infections are inapparent or asymptomatic.*" and goes on to state that "*Rarely (in less than 1% of polio infections), the virus invades and damages or completely destroys the motor neurons of anterior horn cells of the spinal cord and brain stem. This form, known as **paralytic polio** . . .*".

NCIRS also notes that "*About **a tenth** of patients who develop **paralytic polio** can die without appropriate respiratory support when their respiratory muscles are paralysed.*"

Using the widely accepted 5-10% mortality rate as a base, Charlotte Lebeouf², estimated that 40,600 people contracted **paralytic polio** between 1930 and 1988, as sourced from the Australian Bureau of Statistics data. Polio Australia subscribes to this number as being a more accurate reflection of actual numbers of the incidence of paralytic polio than the less reliable notifiable disease records.

Therefore, by extrapolation, those 40,600 cases of **paralytic polio** could equate to more than 4 million Australians being infected with polio over that 58 year period. Of those potential millions infected with polio, movement in and out of Australia and natural attrition due to death needs to be taken into account. The **Australian Polio Register** shows that 15% of polio survivors currently living in Australia contracted polio overseas.

Renowned pathologist, David Bodian³ wrote that, for paralysis to occur, 50% or more of the motor neurons need to have been affected. During rehabilitation, those motor neurons that survived send out new 'sprouts' to take up innervation of the muscle.

¹ The National Centre for Immunisation Research and Surveillance, December 2009, *Poliomyelitis Vaccines for Australian Children: Information for Immunisation Providers*, [NCIRS Fact Sheet](#)

² Lebeouf, C, 1990, *The late effects of Polio: Information for health care providers*, Commonwealth Department of Community Services and Health

³ Bodian D, Cumberland M, 1947, *The rise and decline of poliomyelitis virus levels in infected nervous tissue*, *American Journal of Hygiene*

Many people who were paralysed by polio recovered with varying levels of disability, going on to lead active lives. However, of the remaining 99% of people who were infected but **not paralysed**, many will have also suffered varying degrees of sub-clinical damage to their motor neurons of between 0-49%.

NCIRS states that "*Persons with residual impairment following paralytic poliomyelitis can develop a condition called post polio syndrome (PPS), after a period of prolonged stability (usually 30–40 years). It is characterised by exacerbation of existing muscle weakness coupled with development of weakness/paralysis in previously unaffected muscles. PPS is believed to be caused by degeneration, with age, of over sized motor units created during the recovery process of initial paralytic polio. It is rarely life threatening but has a slow, step-wise, unpredictable course. PPS is not an infectious process and persons who develop PPS do not shed poliovirus.*"

In 2000, a number of peer-reviewed papers noted that:

It should be absolutely understood that patients who were told that they had 'non-paralytic' polio did, in reality, have polio, which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affect other persons with postpolio syndrome.⁴

Asserting that a history of paralytic polio is required for a history of PPS effectively, and incorrectly, says that no neurologic damage was done during acute nonparalytic polio.⁵

PPS must be considered in the differential diagnosis of individuals with unexplained fatigue and weakness ... regardless of whether they report a prior history of paralytic polio.⁶

PPS is a diagnosed 'neurological' condition which, according to the Post-Polio Taskforce⁷ will affect up to 40% of people who had **paralytic** polio. However, the broader condition known as the Late Effects of Polio (LEoP) takes in both PPS and a host of additional 'bio-mechanical' symptoms including scoliosis, kyphosis, respiratory problems, dysphagia, muscle contraction, head, neck and joint aches, chronic tendonitis, bursitis, nerve compression, osteoporosis, arthritis, and fatigue, many of which will impact on virtually **every survivor of polio**.

Polio Australia understands that as both **paralytic** and **non-paralytic** polio survivors age, the neuronal 'sprouts' that supported muscle activity post infection are degenerating as part of the ageing process, causing increased muscle weakness and atrophy, joint pain, and physical disability – even for those who appeared to have no residual disability at all. Many of these symptoms may be confused with premature aging, especially if the person was unaware of – or is unable to acknowledge – having been infected with polio.

When taking into account the 4 million Australians who potentially contracted some form of the poliovirus over the 58 year period reported in Lebeouf's resource, Polio Australia's premise that there are approximately 400,000 people living in Australia today who are experiencing some form of polio's late effects can be considered conservative.

⁴ Johnson, Ernest W MD, *A Clarification of "Nonparalytic" Polio*, American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

⁵ Falconer, Marcia PhD; Bollenbach, Edward MA, *Late Functional Loss in Nonparalytic Polio*, American Journal of Physical Medicine, Vol 79(1), Jan/Feb 2000

⁶ Halstead, Lauro S MD; Silver, Julie K, *Late Functional Loss in Nonparalytic Polio*, American Journal of Physical Medicine, Vol 79(1), Jan/Feb 2000

⁷ The Post-Polio Task Force, 1999, *Post-Polio Syndrome: Questions & Answers*, [Post-Polio Health International website](#)