

Late effects of polio/post-polio syndrome

Background

- 1.1 Poliomyelitis, commonly referred to as 'polio', is a viral infection that was widespread in the Western world until the early 1960s.¹ The virus is transmitted through contaminated food and water, and can result in symptoms of fever, fatigue, headache, vomiting, stiffness in the neck, and pain in the limbs. In a small proportion of cases, the disease causes paralysis, which is often permanent.²
- 1.2 Major polio epidemics occurred in Australia during the late 1930s, early 1940s and the 1950s.³ Today, with the development of effective vaccines in the 1950s and 1960s and a comprehensive vaccination program, Australia is polio-free, having been declared as such by the World Health Organisation (WHO) Western Pacific Region in 2000.⁴ Polio however remains endemic in a handful of countries where international efforts, particularly through the Global Polio Eradication Initiative (GPEI), have not yet achieved a total eradication of the virus.⁵
- 1.3 Notwithstanding that Australia is free of new cases of polio, years after contracting the initial infection increasing numbers of polio survivors have

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- 1 Queensland Health, The Late Effects of Polio - Acute Poliomyelitis, <http://www.health.qld.gov.au/polio/html/acute_poliomyelitis.asp>, viewed 1 June 2012.
 - 2 World Health Organisation (WHO), <http://www.who.int/topics/poliomyelitis/en/>, viewed 7 June 2012.
 - 3 Queensland Health, http://www.health.qld.gov.au/polio/html/manual_download.asp, viewed 6 June 2012, 'The late effects of polio: information for general practitioners', 2001, p. 7.
 - 4 WHO, <http://www.who.int/inf-pr-2000/en/pr2000-71.html>, viewed 6 June 2012.
 - 5 WHO, <http://www.who.int/mediacentre/factsheets/fs114/en/index.html>, viewed 6 June 2012.

developed a range of symptoms, now recognised as post-polio sequelae. The post-polio sequelae cause a range of debilitating health effects, and manifest primarily as biomechanical and neurological symptoms. The condition is referred to broadly as the late effects of polio (LEOP) or, in circumstance where specific clinical diagnostic criteria are satisfied, as post-polio syndrome (PPS).

- 1.4 The symptoms experienced by those with LEOP, which are primarily biomechanical, vary considerably both in range and severity. The added neurological symptoms of PPS provide further health concerns. The symptoms experienced by those suffering LEOP/PPS commonly include:

- general fatigue;
- pain in muscles and/or joints;
- weakness and muscle atrophy;
- muscle spasms/twitching;
- respiratory and sleep problems; and
- difficulties with swallowing and speaking; and
- cold intolerance.⁶

- 1.5 Although there is no accurate data on the prevalence of LEOP/PPS in Australia, it is estimated that thousands of individuals are either affected or at risk of developing the condition. Many of those affected by LEOP/PPS are over 50 years of age, reflecting the fact that polio was an uncommon infection in Australia by the early 1960s. However, migrants to Australia from countries where polio was eradicated later, or where polio continues to be endemic, means that there is cohort of younger polio survivors, who contracted their infection outside of Australia more recently.⁷ This younger group of polio survivors means that LEOP/PPS is a condition that needs to be addressed now and for many years to come in Australia.

6 Queensland Health, 'The late effects of polio: information for general practitioners', 2001, pp. 16-22.

7 Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5.

Conduct of the roundtable

- 1.6 In February 2012 the House of Representatives Standing Committee on Health and Ageing resolved to hold a roundtable to examine a range of issues associated with LEOP/PPS in Australia. The aim of the roundtable was to provide the Committee with a better understanding of the challenges facing those affected by LEOP/PPS and to raise the profile of the condition through discussion in a public forum.
- 1.7 Prior to the roundtable, the Committee issued a paper to participants which highlighted a number of broad themes to guide discussion. The broad themes outlined in the Committee's paper were:
- definition, prevalence and diagnosis of LEOP/PPS;
 - management and treatment of LEOP/PPS; and
 - supports and services for LEOP/PPS.
- 1.8 In addition, Polio Australia as the national peak body providing support and advocacy for polio survivors, prepared a separate paper which was circulated to all participants.
- 1.9 The roundtable was held on 30 March 2012 in Melbourne. The Committee invited key stakeholders involved in the diagnosis, management, support and advocacy for those with LEOP/PPS. Several participants were polio survivors who had developed LEOP/PPS, and were involved in significant advocacy and support capacities as office bearers of various national, state and territory polio associations. The Committee also invited representation from the Australian Government Department of Health and Ageing (DoHA). The participants were:
- Mr Mark Booth, First Assistant Secretary, Primary Care Division, Australian Government Department of Health and Ageing;
 - Dr Stephen de Graaff, private capacity;
 - Mr Arthur Dobson, Secretary/Public Officer, Post Polio Network – Tasmania Inc;
 - Mr Blaise Doran, Physiotherapist and Coordinator, Polio Services Victoria;
 - Mr Brett Howard, President, Polio SA Inc;
 - Ms Mary-ann Liethof, National Program Manager, Polio Australia Inc;

- Dr Margaret Peel, on behalf of the Spinal Injuries Association (Queensland) and Polio Australia Inc;
 - Ms Elizabeth Telford, President, Post Polio Victoria Inc;
 - Dr John Tierney OAM, National Patron, Polio Australia Inc; and
 - Ms Gillian Thomas, President, Polio Australia Inc.
- 1.10 Observers were welcome to attend the day's proceedings. The program for the day and details of the venue were made available on the Parliament of Australia website.⁸
- 1.11 The roundtable opened with a presentation from Ms Gillian Thomas, President of Polio Australia. The three broad themes identified earlier formed the basis of the remainder of the day's discussions. A full transcript of the day's discussion and copies of the slides used by Ms Thomas during her presentation can be accessed from the Parliament of Australia website.⁹

Discussion paper

- 1.12 Drawing primarily on information presented at the roundtable, Chapter 2 identifies issues raised under each of the themes. Discussion showed that roundtable participants were not only knowledgeable and strong advocates for action, but that there was broad consensus among participants on many issues. Therefore, in summarising discussion the Committee has sought to reflect on the range of issues raised and to represent the views of participants. At various points in the paper the Committee expresses its views and conclusions in Committee comment. At the end of the discussion paper the Committee has included a conclusion with a number of key recommendations. The discussion paper will be tabled in Parliament and provided to the Minister for Health for consideration.

8 Parliament of Australia;
http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/leop%20pps/index.htm.

9 Parliament of Australia;
http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/leop%20pps/index.htm.