

Discussion paper on the late effects of polio/post-polio syndrome

House of Representatives
Standing Committee on Health and Ageing

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Foreword

Polio is a crippling and potentially fatal infectious disease. During the 20th Century Australia experienced a number of polio epidemics, affecting many thousands of individuals. International efforts to eradicate polio have been highly successful, largely due to effective vaccines developed in the 1950s and 1960s. These efforts led to a 99 per cent decrease in the number of polio cases worldwide between 1988 and 2010. Australia was officially declared polio-free by the World Health Organisation in 2000.

Despite the eradication of polio in Australia, the disease has left a legacy. Many years after contracting the initial infection and apparently reaching a stable state of recovery, an increasing number of polio survivors are now developing new symptoms. These symptoms, including muscle weakness and pain, fatigue and respiratory compromise, characterise the late effects of polio (LEOP) or post-polio syndrome (PPS). Although it is unclear just how many polio survivors in Australia are affected, LEOP/PPS is a potentially debilitating condition. Even so, the level of awareness about LEOP/PPS among health professionals and the wider community is very low.

In view of this, the Health and Ageing Committee, which I Chair, expressed interest in learning more about LEOP/PPS and its impact on polio survivors, their families and carers. Accordingly, on 30 March 2012 the Committee held a roundtable discussion in Melbourne. Participants at the roundtable included representatives of Polio Australia and associated state-based post-polio networks, which between them provide support and advocacy for Australia's polio survivors. A number of roundtable participants identified themselves as polio survivors directly affected by LEOP/PPS. The roundtable also included representation from health professionals involved with the treatment and clinical management of LEOP/PPS, as well as a representative of the Australian Government Department of Health and Ageing. The roundtable discussions have

formed the basis of the Committee's discussion paper, which I trust adequately reflects the range and scope of issues considered.

On behalf of the Committee I wish to thank all of the roundtable participants. The commitment of participants to providing support and advocacy for polio survivors was evident. In particular the Committee appreciates the contribution made by those directly affected by LEOP/PPS. Despite struggling by the end of the day with LEOP/PPS associated fatigue, the knowledge and experience of this group of individuals provided the Committee with invaluable insights. The Committee also acknowledges and thanks the observers who attended the day's proceedings, including polio survivors, their family members and carers.

Steve Georganas MP
Chair



Membership of the Committee

Chair Mr Steve Georganas MP

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Mr Geoff Lyons MP

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List of abbreviations

ABS	Australian Bureau of Statistics
CPAP	Constant Positive Airway Pressure
DoHA	[Australian Government] Department of Health and Ageing
FaHCSIA	[Australian Government] Department of Families, Housing, Community Services and Indigenous Affairs
GPEI	Global Polio Eradication Initiative
HWA	Health Workforce Australia
LEOP	Late Effects of Polio
MASS	[Queensland Government] Mobility Aids Subsidy Scheme
OT	Occupational Therapist
PCEHR	Personally Controlled Electronic Health Record
PPS	Post-Polio Syndrome
SWEP	[Victorian Government] State Wide Equipment Program
PSV	Polio Services Victoria
WHO	World Health Organisation

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List of recommendations

Recommendation 1

The Committee recommends that the Australian Bureau of Statistics and/or the Australian Institute of Health and Welfare establish mechanisms through inclusion of appropriate questions in existing health and/or disability surveys to estimate and report on the size of the population of polio survivors living in Australia, and the proportion of that population experiencing the late effects of polio/post-polio syndrome.

Recommendation 2

The Committee recommends that the relevant National Boards, in consultation with key stakeholders including peak professional bodies, medical/health educators and training providers, seek to ensure curricula for students includes information on the late effects of polio/post-polio syndrome, to raise awareness of the condition as a possible diagnostic outcome and of best practice for treatment and management.

Recommendation 3

The Committee recommends that Medicare Locals actively engage with Polio Australia and the state-based post-polio associations, with state and territory government departments of health, and with general practitioners to promote activities which will raise awareness of the late effects of polio/post-polio syndrome:

- among practicing health professionals through continuing professional development; and

- in the community through patient education, noting the need to tailor communication to enhance engagement with specific population groups taking into account demographic factors such as age and cultural background.