



# **POLIO AUSTRALIA INCORPORATED**

Representing polio survivors throughout Australia

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*An initiative of the Australian State Post-Polio Networks*

## **Polio ... forgotten, but not gone**



*Submission to the*

### **Senate Community Affairs References Committee**

**Inquiry into planning options and services for people ageing with a disability**

**May 2010**

#### **Polio Australia Incorporated**

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### **Appendix A : Health and Disability Services for Polio Survivors**

## 1. Preface

Polio Australia was incorporated in 2008 and is governed by a Committee of Management made up of state Polio Network representatives. Polio Australia resulted from a national self-funded 'Designing a Future' conference in 2007 where the Networks resolved to establish a national organisation to articulate the needs of polio survivors across Australia through:

- ❖ Educating and informing polio survivors, their families and carers, and the community at large about the late effects of polio.
- ❖ Providing information, education and training to General Practitioners and a range of medical specialists and allied health professionals to improve the diagnosis and management of the late effects of polio.
- ❖ Facilitating the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.
- ❖ Providing outreach to culturally and linguistically diverse and Aboriginal and Torres Strait Islander polio survivors to ensure their diverse needs are being met in a culturally appropriate way.
- ❖ Advising governments on policy development and programs in relation to the late effects of polio.
- ❖ Stimulating research into the late effects of polio.
- ❖ Assisting the state Networks to support polio survivors and their families, friends and carers at the local level.
- ❖ Facilitating and encouraging the co-ordination and further development of activities within and between the state Networks.

## 2. Background

### 2.1 Polio . . . forgotten, but not gone

Polio Australia is very pleased that the Senate Community Affairs References Committee is undertaking this *Inquiry into Planning Options and Services for People Ageing with a Disability*. Access to polio-specific services would make a very significant difference to the quality of life for Australia's hundreds of thousands of individuals and their families who are living with the late effects of polio, and the benefits to the community will continue to grow over time.

For many of Australia's polio survivors, the late effects of polio are causing significant and ongoing problems which impact on all aspects of their daily lives and that of their spouses/carers. Together with peer support and information, many of the symptoms associated with the late effects of polio can be managed through the coordinated efforts of medical and health professionals together with a variety of appropriate community services for people with disabilities and the aged. However, there is currently minimal specialist knowledge and support available or accessible.

In order to help themselves, polio survivors in each state have formed 'Post-Polio Networks' over the last 20 years. These Networks have been proactive in a number of areas including developing support networks, disseminating information, and arranging seminars and conferences. Unfortunately, in the majority of states, the Networks are operating without any funding and this is not a sustainable or adequate model of support.

Polio Australia's information and education programs will lead to prompt diagnosis and effective professional and self-management of the late effects of polio, achieving a comprehensive set of outcomes for polio survivors, their families and carers, health professionals and the community.

Polio Australia's programs will ensure that all polio survivors have access to adequate support and information together with comprehensive and consistent health, disability and aged care services from a range of well-informed and appropriately-educated professionals.

**Polio Australia requires adequate funding to partly redress the current almost total lack of appropriate services for people with the late effects of polio. The unique problems faced by polio survivors require a comprehensive government response. Appendix A to this Submission gives details of Polio Australia's first four-year plan which has been costed at \$8.9 million.**

## 2.2 What are the late effects of polio? Who is affected?

Over the last twenty years much attention has been drawn to the development of new, previously unrecognised, symptoms which occur in people who were thought to have reached a stable level of recovery after the acute disease.

Symptoms of the late effects of polio include unaccustomed fatigue unrelated to activity, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, weakness and muscle atrophy, muscle and joint pain, muscle spasms/twitching, respiratory and sleep problems, swallowing or speaking difficulties. There is also evidence of emotional distress if no assistance is forthcoming.

Many polio survivors who have emerging symptoms still report difficulty in obtaining correct diagnosis and treatment. As time passes, an increasing number of previously 'stable' persons with a history of polio infection report unexpected new symptoms. The large number of survivors who are now experiencing new symptoms has transformed the problem from an individual predicament to a social concern.

Up to 40,000 people were diagnosed with paralytic polio and up to 400,000 with non-paralytic polio in Australia between 1930 and 1988<sup>1</sup>. This latter figure must be increased 10-fold to obtain the estimated number of infected cases during the same period<sup>1,2,3</sup> (up to 4 million people), and the figure does not include people who contracted polio overseas and who have since entered Australia.

Data from the *Late Effects of Disability Clinic* based at the Royal Perth Hospital in Western Australia indicates that the majority of polio clients are in the age range of 50 – 59 (44%), followed by 60 – 69 (24%). *Polio Services Victoria* is a state Department of Human Services funded service located at St Vincent's Hospital Melbourne and their client numbers have been steadily increasing since they commenced in 1997. They reported the mean age at 48 years in 2006, whilst in 2001 it was 69 years. This change in mean age is related to the increase in referrals of clients from a culturally and linguistically diverse background, with particular emphasis on clients from the Indian sub-continent and South East Asia. In 2006, 33% of new referrals for the service were migrants or refugees.

<sup>1</sup> Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers* Commonwealth Department of Community Services and Health, 1990

<sup>2</sup> US Centers for Disease Control, *Epidemiology & Prevention of Vaccine-Preventable Diseases*, 2008

<sup>3</sup> World Health Organisation, *Polio Eradication Program* website <[www.polioeradication.org](http://www.polioeradication.org)>

### 3. Polio Australia's Programs

#### Providing options and services for people ageing with the late effects of polio

The late effects of polio will become an increasing issue for communities around Australia as the population ages, and as the community diversifies through immigration. Without urgent and appropriately funded interventions now, the cost to the health, disability and ageing portfolios will continually increase over the coming years.

To put in place a long overdue program to meet the priority needs of polio survivors, Polio Australia requires the support of federal funding to implement a series of interrelated projects over an initial four-year period [Appendix A]. Polio Australia's programs will ensure that the quality of life of polio survivors is maintained; that they continue in their role as valued, contributing members of society; and that otherwise escalating costs to the community are contained.

Although there are currently very few health services knowledgeable about working with polio survivors, those health professionals who have participated in state Post-Polio Network activities have reported that they gain an increased understanding and better resources to assist their patients. Polio Australia's programs will extend this understanding and related resources across Australia.

The increased knowledge base across the health sector will lead to more accurate assessment, diagnosis and management for people experiencing the late effects of polio, with a corresponding decrease in federal health expenditure.

Polio Australia's programs will ensure that polio survivors develop the requisite skills, understanding and practical strategies in relation to ageing with a disability, including sourcing and accessing community resources.

Polio survivors will also be empowered to educate their own health practitioners using accurate, credible, current and well-researched information.

There will be a reduced impact on the acute care and health sectors as more polio survivors are diagnosed and taught how to effectively manage their chronic condition.

Similarly, there will be a reduced impact on the disability and aged care sectors as more polio survivors become aware of their options in maintaining mobility and independence.

In summary, the requested funding will over time reduce the health, disability and aged care resources which will otherwise be increasingly required as polio survivors age with their chronic condition. The research project to be funded in the first year will further explore the unacceptable cost to the community and to the government of continuing to do nothing.

## 4. Initiatives Supported by Polio Australia

### 4.1 Universal Housing Standard

As people experiencing the late effects of polio face increased physical and mobility limitations, Polio Australia supports the development of a Universal Housing Standard which, at a minimum, includes the following features for every new home:

- a. A clear pathway to a step-free, well-lit entry with access to street/car parking.
- b. Appropriate lighting evenly distributed throughout the house.
- c. Clearly identifiable light switches, easy-to-reach controls and handles.
- d. Places for someone sitting or standing.
- e. Reinforced walls in the bathroom, shower and toilet.
- f. Wide doorways and corridors (minimum clear opening width of 850mm).
- g. A straight staircase adjacent to a load-bearing wall.
- h. Slip-resistant flooring.
- i. Open-plan kitchen, lounge and bathroom with step-free shower.
- j. Open-plan room on entry level that can be used as a bedroom.
- k. Accessible toilet and bathroom on entry level.

**Note:** Many Polio Survivors may currently, or in future, be wheelchairs users or unable to lift their legs due to muscle atrophy.

### 4.2 National Disability Insurance Scheme (NDIS)

As indicated on the NDIS website, *“Almost every Australian has cared, or is caring, for a family member with a disability, or knows of a family doing so. Many of these families fall through a huge gap in Australia's social services network.”*

Polio Australia believes this summary represents the predicament of people experiencing the late effects of polio, and their spouses/carers. As Polio Survivors increasingly require more expensive aids and equipment to maintain mobility and independence, the prohibitive cost is adversely impacting on quality of life.

Polio Australia further endorses the NDIS position that *“Without a comprehensive funding plan to meet future need, Australia faces social catastrophe as an entire generation of ageing carers die, other carers and people with disabilities become increasingly isolated from the labour force and the community, and many more families collapse under the strain.”*

## 5. Recommendations

Polio Australia requests that the Senate Community Affairs References Committee consider the following recommendations:

- ❖ Federal funding to support Polio Australia in implementing a series of interrelated projects over a four-year period (see Appendix A). Polio Australia's programs will ensure that the quality of life of polio survivors is maintained; that they continue in their role as valued, contributing members of society; and that otherwise escalating costs to the community are contained.
- ❖ Appropriately funded interventions such as polio-specific clinics in each state (see Polio Services Victoria – Page 5) to reduce the cost to the health, disability and ageing portfolios which will continue to increase over the coming years.
- ❖ A research project be funded to identify specific numbers of polio survivors in Australia and the unacceptable cost to the community and to the government of continuing to do nothing.

**Authorised by:**

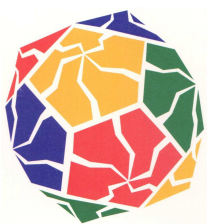


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### **Appendix A**

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## Appendix A : Table of Contents

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	❖ Year One	
	❖ Year Two	
	❖ Year Three	
	❖ Year Four	

## 1. Priority Funding Needs

### 1.1 Information

- ❖ Develop and promote an information-based website.
- ❖ Source and produce standard research-based material for information kits.
- ❖ Develop and promote Polio Australia as a national authority for polio-related information and centre of expertise.
- ❖ Align annual Polio Awareness Week and promote information campaigns across Australia.
- ❖ Commission a research project to determine numbers of polio survivors living in Australia, including younger migrants and Aboriginal and Torres Strait Island people and produce a report on the economic impact of the late effects of polio in Australia.

### 1.2 Chronic Condition Self-Management Education

- ❖ Develop chronic condition self management program to be delivered, for example, as:
  - State-based Health and Wellness Retreats.
  - Regional community education sessions.
  - Consumer-based adaptation of health professional podcast on website.
  - Annual, rotating state-based conferences/workshops to disseminate and promote best-practice self-management for Australian polio survivors.

### 1.3 General Practice Collaboration

- ❖ Develop relationship with Australian Divisions of General Practice to work on strategies for engaging GP's.
- ❖ Recruit GP's with knowledge of the late effects of polio to write journal articles and facilitate podcast or face-to-face in-services for their peers.
- ❖ Produce a best-practice clinical assessment film which can be used as a podcast for GP's Continuing Medical Education.

### 1.4 Allied Health Professional Collaboration

- ❖ Adapt the best-practice clinical assessment film which can be used as a podcast for various allied health professional's Continuing Professional Development.
- ❖ Recruit allied health professionals with knowledge of the late effects of polio to write journal articles and facilitate podcast or face to face in-services for their peers.

## 2. Budget

### Year One

Website development, production and promotion	30,000
Information Pack development, production and distribution	40,000
Chronic Condition Self-Management Education program development	200,000
CME & CPD Podcast film development and production for GP's & AHP's	300,000
Research Project & Report	120,000
Development of media campaign for Polio Awareness	200,000
Associated administrative functions	200,000
<b>Total</b>	<b>1,090,000</b>

### Year Two

Website maintenance and promotion	20,000
Chronic Condition Self-Management Education facilitation across states	800,000
CME & CPD Podcast film distribution and promotion	200,000
Polio Awareness campaigns	300,000
Professional Partnership Development	200,000
Associated administrative functions	300,000
<b>Total</b>	<b>1,820,000</b>

### Year Three

Website maintenance and promotion	30,000
Chronic Condition Self-Management Education facilitation across states	900,000
CME & CPD Podcast film assessment and review	50,000
Polio Awareness campaigns	500,000
Professional Partnership Development	400,000
Associated administrative functions	500,000
<b>Total</b>	<b>2,380,000</b>

### Year Four

Polio Australia Projects Survey development, distribution and evaluation	30,000
Website maintenance and promotion	20,000
Chronic Condition Self-Management Education facilitation across states	1,200,000
Polio Awareness campaigns	800,000
Professional Partnership development	800,000
Associated administrative functions	800,000
<b>Total</b>	<b>3,650,000</b>

**TOTAL OVER 4 YEARS** **\$8,940,000**