



Proposal

Polio Australia

A National Educator

on the late effects of polio



Polio ... forgotten, but not gone

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Executive Summary

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. Many of the symptoms associated with the late effects of polio can be managed through the coordinated efforts of medical and allied health professionals, in partnership with polio survivors. However, there is minimal specialist medical 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 organisations have been proactive in developing support networks, disseminating information, and arranging seminars and conferences. More recently the state Networks have formed Polio Australia which is tasked with developing national polio resources in collaboration with medical professionals and polio survivors. Polio Australia's programs will include ♦ formal education to a wide range of health professionals, articulating the issues and needs of polio survivors ♦ authoritative information on the late effects of polio and their management via a dedicated website, multi-media and printed materials ♦ identification of, and information and support to, polio survivors nationally ♦ promotion of centres of excellence for management of, and research into, the late effects of polio ♦ forging linkages with relevant expert individuals and organisations ♦ promoting immunisation ♦ engaging the general public.

This proposal seeks \$4 million over four years from the Federal Government to achieve this comprehensive set of outcomes. In year 1 the emphasis will be on medical education programs which will lead to prompt diagnosis and effective management of the late effects of polio thereby realising savings across many areas of existing government expenditure. In following years Polio Australia will build on this foundation to target the education of polio survivors, allied health professionals, and a variety of support services.

The funding will reduce unnecessary Government expenditure while at the same time ensure that all polio survivors have access to comprehensive, consistent health care from a range of well-informed and educated professionals together with peer support and information.



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Introduction

Polio (poliomyelitis or infantile paralysis) is now a disease that has virtually been forgotten by our community and health professionals. Although vaccination programs beginning in the late 1950s have prevented new infections in Australia, polio survivors form the largest single disability group in the country. Professionals with first-hand experience of the disease have long since retired and there is an urgent and growing need for Australians to become re-acquainted with polio and its late effects.

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. These symptoms are known collectively as “the late effects of polio” Many polio survivors who have emerging symptoms still report difficulty in obtaining correct diagnosis and treatment. The large number of survivors who are now experiencing new symptoms has transformed the problem from an individual predicament to a social concern.

In recognition of the need for support for those experiencing the late effects of polio, Post-Polio Networks were established in all Australian states in the late 1980’s and early 1990’s. These groups continue to provide information and support services on a voluntary basis to large numbers of their peers and health professionals, generally without the benefit of any public funding.

More recently, the state Post-Polio Networks have established a national educator, ‘Polio Australia’.

This submission seeks funding to enable Polio Australia to fulfil its mandate of putting in place education programs for health professionals, polio survivors and the community which will in turn lead to the provision of appropriate, adequate and consistent health and ancillary services to polio survivors throughout Australia. Polio survivors as yet unaware of the late effects of polio (or even unaware that they contracted the disease) will also benefit from a broad-ranging community awareness program.



Education is the key

\$4 million dollars over 4 years is being requested for a federally-funded national polio education and information program designed, managed and presented by Polio Australia in collaboration with all stakeholders. Initially, the program will be targeted towards health professionals: General Practitioners and Medical Specialists. The emphasis on medical education programs will lead to prompt diagnosis and effective management of the late effects of polio thereby realising savings across many areas of existing government expenditure. In a staged approach, the program will then bring best-practice information about the late effects of polio to polio survivors, allied health professionals and community services.

A budget is attached at Appendix A.

Year 1 - Education Program for Health Practitioners

People who were diagnosed with paralytic polio and have obviously affected limbs still have trouble convincing some doctors that the late effects are “real” and not psychosomatic or simply the result, for example, of using crutches for too long. People with a history of non-paralytic polio have even greater difficulty convincing the medical establishment that their fatigue, muscle weakness and pain are related to childhood polio. These people have a history of polio, either documented by hospitals or by family records and stories, but there are many people who had polio and don’t even know it. Members of all of these groups can and do experience the late effects of polio, as discussed further in **Appendix C**.

The lack of awareness amongst health practitioners of the late effects of polio is costly not only in terms of the impact on polio survivors who are mis-diagnosed and receive inadequate treatment and support, but also for the government in funding the health and community care systems. Rather than receiving a diagnosis followed by the implementation of a comprehensive and well coordinated care plan, polio survivors are forced to consult with general practitioners, physicians, neurologists, therapists



and other health practitioners who all have differing opinions about the cause of their symptoms. Not only are these consultations costly, they also delay rehabilitation and treatment which can lead to deterioration, hospitalisation and increased dependence on the health system.

Funding for an extensive national medical education program, followed by a community awareness raising campaign, has the potential to save millions of dollars in the longer term, as health professionals and polio survivors understand the symptoms and management of the late effects of polio.

Polio Australia will target the first phase of funding to provide the following:

- Nationally-consistent formal training to GPs and a range of medical specialists about polio, its late effects, the diagnosis of late effects, treatment modalities and lifestyle interventions.
- Ongoing dissemination of information to health practitioners through networking via the Divisions of GPs and presentations at medical conferences.
- A dedicated website for health practitioners. The development and maintenance of a national polio website enabling health practitioners to seek relevant and current information about the late effects of polio, and containing tools and guidelines for diagnosing and managing the condition. This would also provide the opportunity for interactive communication forums and questions and answers.
- DVD Information Pack. A visual resource for health practitioners to provide them with information, education and best-practice management.
- Education Materials. A range of printed materials in support of the formal program.



- Peer Networks. The development of a national interactive peer network for health professionals who have an interest and/or expertise in the late effects of polio, in collaboration with overseas experts in the field.
- Corporate Partnerships. Development of partnerships with socially responsible corporations and businesses with the aim of augmenting government funding. This will assist with the second phase of this funding proposal where Polio Australia broadens the scope to include a community awareness program.

Years 2, 3 and 4 – Awareness, education and support for polio survivors

There are many polio survivors who are as yet unaware of the late effects of polio and who do not therefore appreciate that they are at risk of developing them. Indeed, as elaborated on in **Appendix C**, there are many more people who do not even realise that they contracted the disease either in their own right or from their diagnosed siblings or friends. Awareness of the ongoing need for polio immunisation is also essential. Therefore this awareness campaign will focus primarily on:

- Awareness and understanding of the incidence of polio in the community.
- Awareness and understanding of the late effects of polio.
- Identification of polio survivors “hidden” in the community.
- Education of polio survivors, their families and carers, and the community at large about the late effects of polio and their management.
- Awareness of the resources available to polio survivors to help them maintain their quality of life.
- Targeting culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) polio survivors and providing outreach support to ensure their diverse needs are being met in a culturally appropriate way.



- Supporting and promoting polio immunisation at a national level, and providing assistance to the state Networks to do so at the local level.
- Stimulating research into the late effects of polio.

A look at the late effects of polio

Polio (described in more detail in **Appendix B**) was previously considered to be a self-limiting disease, once the acute stage was over. The amount of residual damage determined the degree of recovery, which was thought to be stable once optimum function had been achieved. However, it is now well established that polio has a second, slowly progressive degenerative phase, unrelated to normal ageing.

As time passes, an increasing number of previously “stable” persons with a history of polio infection report unexpected new symptoms. The time lag from the initial infection to the second phase varies but is commonly approximately 30 years. The onset is usually slow and steady. It may occasionally develop suddenly and progress at an irregular pace. Symptoms sometimes commence after a period of physical or emotional strain, or after a period of immobility (for example: disease, surgery).

Symptoms 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 problems, swallowing or speaking difficulties, depression and anxiety.

Since the 1980s there has been a marked increase in the number of scientific articles and reports in the popular press on this subject. The most widely accepted hypothesis for the cause of the late effects is that they result from the degeneration of motor neurones which sprouted new connections to compensate for the nerves killed by the polio virus. Other contributing factors in the development of the late effects may also include the overuse or disuse of muscles, and the ageing process. However, ageing alone is not the cause, as new symptoms may, in fact, commence at any age



and commonly well before the age of 60, when significant age-related loss of motor neurones ordinarily occurs.

Data from the *Late Effects of Disability Clinic* in Western Australia suggests that the majority of polio clients are in the age range of 50 – 59 (44%), followed by 60 – 69 (24%). The number of clients accessing *Polio Services Victoria* has been increasing, and the mean age of new clients is now 48 years (2006), whilst in 2001 it was 69 years. This change in mean age is related to the increase in referrals of clients from a CALD 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.

Conclusion

Polio Australia will draw on the considerable expertise in the existing state Post-Polio Networks to achieve success in the proposed national education programs. Polio Australia will provide nationally-consistent information, education and training to health practitioners and allied health professionals to improve the diagnosis and management of the late effects of polio. Through a wide-ranging awareness campaign Polio Australia will also work to identify the many tens of thousands of polio survivors “hidden” in the Australian community to provide them with relevant information, education and support.

The late effects of polio will become an increasing issue for communities around Australia as the population ages, and as the community diversifies with people from regions including the Indian sub-continent choosing Australia as their home. Polio Australia’s education programs will ensure that the medical profession has the resources to diagnose and treat the late effects. The quality of life of polio survivors will be maintained, and they will continue to be valued, contributing members of society.



Appendix A

Polio Education and Awareness Budget

Expenditure Year 1

Health Practitioners

Formal training, conference presentations, networking	130 000
Website development, production and promotion	125 000
DVD development, production and distribution	125 000
Information Pack development, production and distribution	115 000
Corporate Partnership development for Years 2, 3, 4	80 000
Associated administrative functions	145 000
TOTAL	720 000

Expenditure Year 2

Health Practitioners and Polio Survivors

Costs	Year 2	850 000
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Expenditure Year 3

Health Practitioners, Polio Survivors and Allied Health Professionals

Costs	Year 3	1 180 000
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Expenditure Year 4

Health Practitioners, Polio Survivors, Allied Health Professionals, Community Providers and the General Public

Costs	Year 4	1 250 000
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Total Request for Funding **4 000 000**



Appendix B

What is polio?

Polio (poliomyelitis, or infantile paralysis as it has also been called) is a viral disease that was common in the Western world until the early 1960s. Polio is caused by an enterovirus of which there are three distinct strains, and none of these strains provide cross-immunity to the others. Infection occurs through the faecal-oral route, through direct or indirect contact. Polio first came under notice in Australia at the end of the 19th century. There were two particularly large epidemic outbreaks in Australia, one in the late 1930s and early 1940s and the other about ten years later, but polio infections in fact occurred every year and the disease remained common into the early 1960s.

Paralytic polio is the most serious type of polio and causes paralysis through the virus invading the central nervous system, spinal cord and the brain. Problems associated with paralytic polio include weakness, paralysis, serious breathing problems, or death. The recovery from paralytic polio varies, but people who suffer paralysis from the infection have muscle weakness and related disability to a greater or lesser extent for the rest of their lives.

Residual complications include:

- muscle paresis and paralysis, which may result in skeletal deformities, joint contractures and movement disability;
- growth retardation of an affected limb(s);
- osteoporosis and subsequent fractures due to inactivity;
- pain from wear and tear due to abnormal body mechanics;
- compression neuropathy from the use of crutches, callipers or a wheelchair;
- respiratory insufficiency;
- intolerance to cold due to circulatory disturbances.



The diagnostic distinction between “paralytic” and “non-paralytic” polio was entirely arbitrary during the epidemics of the last century. In fact, the category of non-paralytic polio contained many patients with mild or temporary paralysis and with encephalitis, which occurs in people reaching the later stages of this illness. Modern studies indicate that overt paralysis in these people depends entirely on the percentage of spinal nerve cells destroyed. For damage to be visible as weakness or paralysis at least 50% to 60% of the nerves controlling muscular action must be damaged or destroyed.

Up to 40,000 people were diagnosed with paralytic polio in Australia from 1930 onwards. Incidence rates of between 10 and 20 cases of paralytic polio per 100,000 inhabitants each year were commonly experienced during epidemics. These figures must be increased 100-fold to obtain the estimated number of infected cases during the same time period (up to 4 million people), and they do not include people who contracted polio overseas and who have since entered Australia. Between 1930 and 1960 there were approximately 2,000 reported deaths due to acute polio. [Reference: Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers*, Commonwealth Department of Community Services and Health 1990]

With the advent of the polio vaccines (Salk was introduced in Australia in 1956 and Sabin in 1966) and subsequent successful mass immunisation programs, new cases of the disease were eliminated in Australia as well as in all other developed countries.

Although acute poliomyelitis is a rare condition in Australia today, there are many thousands of people who have been left with a wide range of disabilities, which restrict and impede the activities of their daily living. In addition, people who contracted both paralytic and non-paralytic polio are now experiencing the late effects of polio, are increasingly seeking information on managing the condition, and are in need of comprehensive support services.



Appendix C

The late effects of polio – some statistics

What are the late effects of polio?

- Unaccustomed fatigue, both general fatigue and muscle fatigue.
- New muscle weakness. This may be located in muscles originally affected by polio as well as those thought to be unaffected by the disease.
- Pain in muscles and joints.
- New breathing difficulties.
- Muscle cramping and twitching.
- Swallowing difficulties and voice changes.
- Muscle atrophy (loss of muscle bulk).
- Sleep-disordered breathing.
- Increased cold intolerance.

How prevalent are the late effects?

International researchers have broken down polio statistics as follows:

- In 100 cases of polio (both diagnosed and undiagnosed cases), only 1 person will have paralytic polio.
- Ten people will have non-paralytic polio.
- All of these people who were diagnosed with paralytic or non-paralytic polio will have some nervous system damage. This means they may develop the late effects of polio many years after contracting the virus.
- The remaining 89 people do not even know they had polio. The majority will have had no symptoms at all. Some had a fleeting stomach upset and may have felt slightly unwell, but none of these will have had nerve damage. However somewhere between 10 and 20 people will have had undiagnosed polio, possibly even paralytic polio. These people are all at risk of developing the late effects but will not be aware of the cause of their symptoms.



Therefore, survivors with less damage who may have had a minor illness, and some people who were asymptomatic can still present many years later with classic late effect symptoms.

Relating the above figures to the Australian experience, up to 40,000 people contracted paralytic polio in this country between 1930 and 1988. As noted above, these figures must be increased 100-fold to obtain the estimated number of infected cases during the same period (up to 4 million people). The figures do not include people who contracted polio overseas and who have since entered Australia. [Reference: Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers*, Commonwealth Department of Community Services and Health 1990]

The Post-Polio Network (NSW) Inc has undertaken two research projects (1998 and 2006) to quantify the extent and impact of the late effects of polio on the lives of those who contracted the disease and on those who care for them. The 2006 research provides an unusual and valuable opportunity for comparison between two studies which had many of the participants in common and in which many of the issues addressed were the same.

Major findings of the Network's 2006 research report *Polio – The Living Legacy* include:

- Almost all polio survivors experience the debilitating problems of muscle weakness (92%) and fatigue (89%).
- At least 64% report, in order of frequency, muscle pain, joint pain, sensitivity to cold, muscle atrophy, tendency to fall, sleep problems and muscle cramps.
- More than half of those surveyed experience muscle twitching and problems with finding words.
- Breathing difficulties, headaches, change in voice and swallowing difficulties were reported by between 37% and 43% of respondents.



While these conditions may be exacerbated by ageing, they are not directly age related as most difficulties are experienced across the full age range of participants, with younger respondents experiencing many problems equally, or even at a greater rate, than older participants, and sooner than would be considered to be the result of ageing in the general population. It is also apparent that many of these difficulties have increased over the ten years between surveys.

Research participants also provided information on the growing difficulties experienced with a number of aspects of personal life including personal care; undertaking household tasks; reliance on family; mobility and transport; employment; exercise; and the use of aids and appliances.

The overall picture is of a group of people who have many physical limitations and many difficulties in managing daily life. At the same time, they have contributed greatly to Australian society – they have raised families, excelled in their chosen professions, and are now coping with their increasing disability with determination in the face of limited and fragmented services. Taking survivors and their families together, the number of people feeling the impact of the late effects of polio on their lives and requiring information, support, and knowledgeable health and ancillary services easily trebles from the number who actually contracted the disease.