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POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

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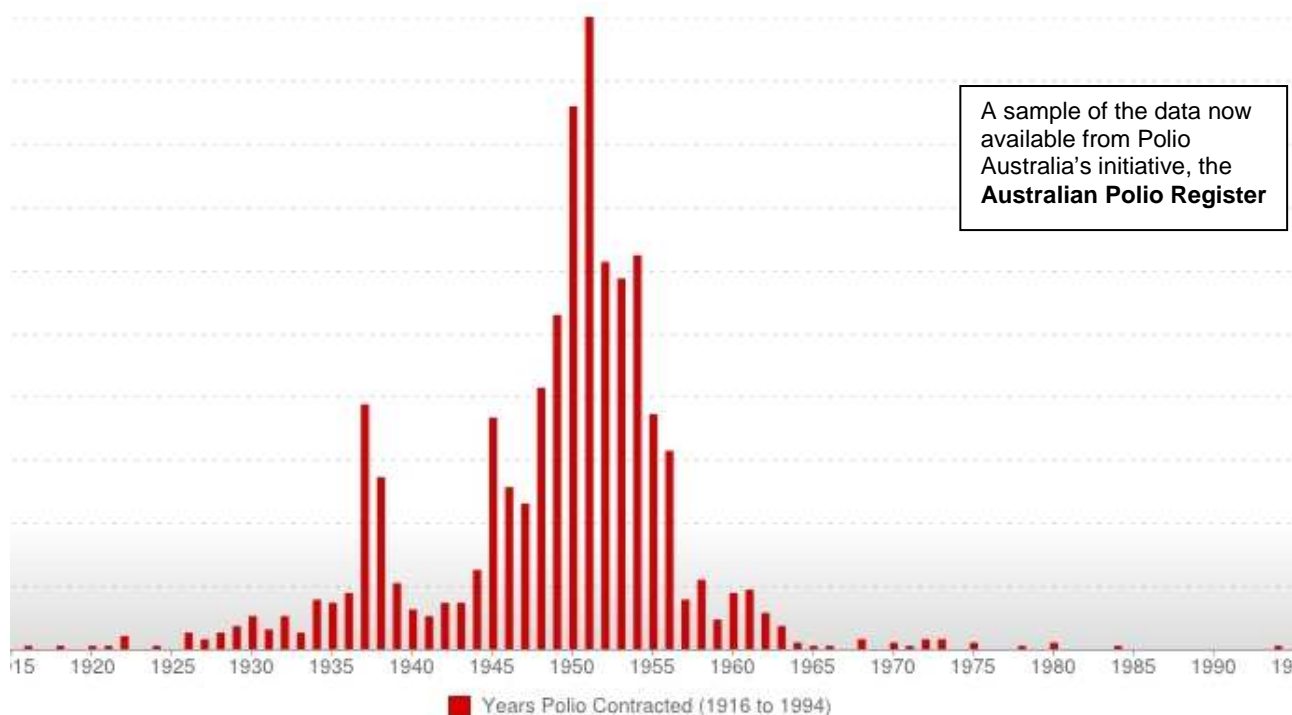
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HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH & AGEING

Roundtable Forum 30 March 2012
Services for Polio Survivors in Australia

Polio Australia Discussion Paper



National Patron: Dr John Tierney, PhD, OAM, Federal Senator for NSW 1991 - 2005

POLIO AUSTRALIA DISCUSSION PAPER RECOMMENDATIONS

OVERALL

Recommendation 1: That Polio Australia be resourced to develop, in conjunction with all stakeholders, a **National Polio Strategy** to establish as a national health priority the diagnosis and management of the late effects of polio (LEOP) and the ongoing support of polio survivors and their families.

DIAGNOSIS

Recommendation 2: That Polio Australia be resourced, under the guidance of its Clinical Advisory Group, to develop and disseminate a clinical practice framework for LEOP diagnosis, including related training for health professionals.

Recommendation 3: That a program be commenced to improve diagnosis of LEOP through the enhancement/establishment of polio-specific specialist services throughout Australia, including flexible LEOP Clinic models for metropolitan, rural and remote areas.

MANAGEMENT

Recommendation 4: That Polio Australia be resourced, under the guidance of its Clinical Advisory Group, to develop and disseminate nationally consistent LEOP management information and best-practice, evidence-based clinical recommendations to GPs, specialists in a range of disciplines, allied health professionals, medical students, health centres and the polio community.

Recommendation 5: That a program be established to design and implement LEOP education programs for Hospital, Nursing Home and Clinic staff.

Recommendation 6: That Polio Australia be resourced to continue the nationwide roll out of its annual residential chronic disease self-management programs for polio survivors and their families.

Recommendation 7: That a recommendation be made to the COAG Health and Ageing Ministerial Council for the relevant state and territory governments to expand the specialist LEOP services in Victoria and WA, and establish at least one *new* specialist LEOP service in another State/Territory by 2015, with specialist LEOP services in the remaining States/Territories to follow in an agreed timeframe, with joint funding provided by the federal and state/territory governments on a dollar for dollar basis.

Recommendation 8: That a recommendation be made to the COAG Health and Ageing Ministerial Council for state and territory governments to provide appropriate funding for medical equipment and aids to maximize the quality of life for those experiencing LEOP.

Recommendation 9: That anomalies in existing Commonwealth Government programs/initiatives which limit their suitability for polio survivors be addressed.

SUPPORT

Recommendation 10: That Polio Australia be resourced to continue its programs to inform and support polio survivors and their families.

Recommendation 11: That Polio Australia be resourced to appoint community education officers to give practical assistance to peer support polio networks to ensure their ongoing viability and availability to polio survivors throughout Australia.

Recommendation 12: That Polio Australia be resourced to conduct a national awareness campaign for survivors to sign up to the Australian Polio Register, and for ongoing maintenance of the Register.

Recommendation 13: That existing efforts to quantify the numbers of polio survivors at risk of experiencing LEOP be enhanced through inclusion of appropriate questions on the Australian Health Survey.

Recommendation 14: That resources be provided to research and determine the burden of LEOP on the Australian community.

Recommendation 15: That a study be initiated into how polio impacted on the ATSI communities.

Recommendation 16: That resources be provided to develop a community awareness media campaign targeting CALD and ATSI communities.

Recommendation 17: That resources be provided to produce LEOP information in a range of ethnic translations.

Recommendation 18: That LEOP information be placed in relevant Government and publications and websites.

1. WHAT ARE THE LATE EFFECTS OF POLIO ?

- For over twenty years, increasing numbers of previously 'stable' polio survivors have reported the onset of debilitating symptoms including severe fatigue, new muscle weakness, and pain in muscles and joints. Some survivors develop potentially life-threatening respiratory and swallowing problems requiring mechanical respiratory equipment to survive.
- These symptoms are collectively known as the late effects of polio (LEOP) (*in some literature the term is used interchangeably with the most severe form of LEOP known as Post-Polio Syndrome (PPS)*).
- LEOP can be experienced whether or not people contracted paralytic or non-paralytic polio, or indeed whether they were aware of their original polio infection.
- Once the Salk polio vaccine was introduced into Australia in the mid 1950s, polio was considered to be a 'solved problem' and support services which had evolved over the preceding 40 or so years gradually closed, or changed to cater for other disabilities. At that time no-one knew of LEOP, and its negative impact on mobility, independence, coping strategies and overall life quality issues.
- As a result of polio epidemics, hundreds of thousands of polio survivors living in Australia today have a wide range of chronic LEOP conditions that increasingly restrict and impede their daily lives. Many polio survivors are forced into early retirement with consequent loss of financial security and self-esteem. With better management of LEOP, polio survivors could work longer, retire later, pay more taxes and be less of a financial burden on the health and tax system.
- LEOP were not generally recognised in Australia until the 1980s, but 25 years later the majority of health professionals still have limited understanding of this chronic condition. Specialist health and disability services are largely non-existent and urgently required.
- For a quarter of a century the only information and support services available to polio survivors have been provided by their peers on an overwhelmingly volunteer self-funded basis.

Case Study – “I was unable to get a diagnosis until the Polio Network gave me a PPS specialist name. I cried with relief throughout the assessment to find someone who understood what I was going through, gave my GP management ideas, and was prescribed calipers. My life changed.”

2. HOW MANY POLIO SURVIVORS LIVE IN AUSTRALIA ?

- Up to 40,000 people were diagnosed with paralytic polio in Australia between 1930 and 1988¹. A further 400,000 contracted non-paralytic polio during the same period, while the estimated number of infected cases is up to 4 million people^{1,2,3}. These figures do not include those who contracted polio overseas and who have since entered Australia.
- Analysis of data from Polio Australia's initiative, the *Australian Polio Register*, shows that 84% of polio survivors currently living in Australia contracted polio in this country, while the remaining 16% contracted polio in almost 50 different overseas countries.
- The Register also shows that 32% of polio survivors currently live in NSW, 21% in Victoria, 14% in WA, 13% in Queensland, 12% in SA, 6% in Tasmania, and 2% in the ACT and NT.
- There is only one polio-specific health clinic in Australia (in Vic), and a small *Late Effects of Disability Clinic* (LEOD) (in WA). Demographic data from the LEOD Clinic indicates that the majority of polio clients are aged 50 – 59 (44%), followed by 60 – 69 (24%). Data from *Polio Services Victoria* (PSV) shows that client numbers have steadily increased year after year. These demographics are supported by emerging data from the Australian Polio Register.
- In parallel with data from the Australian Polio Register, Polio Australia has negotiated with the ANU to research reported polio infections in Australia last century and extrapolate the numbers (*taking account of the known under-reporting of both paralytic and non-paralytic cases, death rates, and immigration rates*) to estimate the number of polio survivors living in Australia today.

See Recommendations 1, 10, 11, 12, 13, 14, 15, 16, 17, 18

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

² US Centers for Disease Control and Prevention, *Epidemiology & Prevention of Vaccine-Preventable Diseases*, 2008

³ World Health Organisation, *Polio Eradication Program* website <www.polioeradication.org>

3. WHY ARE SPECIALIST SERVICES REQUIRED FOR POLIO SURVIVORS ?

3.1 Health professional skills Medical faculties no longer teach students about polio as they consider it a disease of the past. As a result, the late effects go unrecognised by up to 90% of GPs and allied health professionals. People who survived the polio infection now search endlessly for medical help to manage the complex manifestations of its aftermath. Worse still, frequent misdiagnosis means the best medical endeavours often exacerbate the condition by over stressing already fragile polio nerves and muscles.

A recent survey carried out on behalf of the British Polio Fellowship⁴ revealed that 55% of GPs are unable to diagnose the debilitating effects of PPS, and it takes a shocking average of six years to get a diagnosis. The GP survey also showed that only 18% of GPs know how to treat PPS once diagnosed.

See Recommendations 1, 2, 3, 4

3.2 Burden of chronicity Many polio survivors who walked independently must now use braces, crutches or wheelchairs and make changes to their work and home lives to stave off declining independence and the risk of admittance to expensive care facilities. Costs to the taxpayer of acute care episodes from falls and breathing issues, for example, are also significant. Polio survivors who remain in their homes increasingly rely on ageing partners to help undertake daily activities.

See Recommendations 5, 6, 8

4. DIAGNOSIS OF THE LATE EFFECTS OF POLIO

Issues:

The LEOP represent a wide range of symptoms that affect tens of thousands of polio survivors in Australia. Increasing numbers of polios search for help, but without success because medical students are not taught to diagnose and deal with the unique problems polio survivors face. The few health professionals with knowledge of LEOP are mainly accessed via two state-funded specialist clinics (*see Section 1*) which themselves have extensive waiting lists, leaving the great majority of survivors across Australia with no access at all to essential specialist clinics.

What is needed:

- Increased LEOP knowledge base across the health sector to ensure prompt and accurate assessment, diagnosis and effective management strategies for polio survivors.
- Flexible LEOP Clinic models for metropolitan, rural and remote areas.
- Access to appropriate information to empower polio survivors to educate their own health practitioners using accurate, credible, current and well-researched LEOP information.

Polio Australia – some achievements to date:

- Created the Clinical Advisory Group, a multi-disciplinary panel of health professionals who work together to develop criteria for LEOP *Best Practice Clinical Recommendations*.
- Health professionals invited to participate in Polio Australia's annual self-management residential programs or who have been involved with state Polio Network activities report an increased understanding of LEOP and so are much better placed to recommend services and resources to assist their polio patients.
- Published national newsletters on print and web-based platforms to share LEOP management strategies and research work.

Case study – *“It is great to know of someone I can call who understands and cares about my needs. I battled on for years before finding the Polio Network. Now I know my feelings of tiredness and frustration are from Post Polio Syndrome (PPS) and not, as many claimed, ‘all in my head’.”*

Case study (feedback following attendance at a Polio Australia self-management residential) – *“For me it was a life-changing experience! It seemed to offer everything we needed: great plenary sessions, excellent small group discussions, one-to-one opportunities with professionals, and the chance to share all these experiences with one’s partner. Beyond that, there was the informal chance to make connections and share experiences with other polio survivors. I’ve already made three important follow-up appointments.”*

See Recommendations 1, 2, 3, 4, 5, 6, 7

⁴ The British Polio Fellowship <<http://www.britishpolio.org.uk/CampaignsAndNews/Campaigns.aspx>>

5. MANAGEMENT OF THE LATE EFFECTS OF POLIO

5.1 The capacity of Australian health services to plan effective management strategies

Issues:

Because few health professionals understand LEOP, most polio survivors with new symptoms fail to find medical services able to help them. With minimal access to specialist services, diagnosis and management of LEOP's chronic condition is now of paramount importance to polio survivors. Older polio survivors face premature admission into nursing homes as they lose the ability to care for themselves, putting further pressure on an overburdened health system.

Under-reporting of original polio infections and lack of understanding of the numbers of polio survivors facing LEOP have reduced the ability of Australian health services to address the current needs of LEOP sufferers and plan for necessary services.

Case study – *“If it wasn't for the Polio Network I would not have found suitable medical help to manage my PPS tiredness and pain. The Polio Network leaflets also helped my GP. Now I know there is a reason for my pain and weakness and it has a name.”*

See Recommendations 1, 4, 5, 6, 7, 12, 13, 14

5.2 The value of existing volunteer peer networks and their capacity to continue providing information and support

Issues:

With only one specialist LEOP Clinic (in Vic) and one LEOD Clinic (in WA) to diagnose and prescribe management strategies, and with GPs largely unaware of LEOP, polio survivors have limited options for accessing information and support. For example, they trawl the internet, they search for and join a state or regional support group, and they increasingly contact Polio Australia. Nearly all these options are maintained by polio survivors, now themselves struggling with debilitating LEOP effects.

The State Polio Networks have been providing their largely volunteer services for up to twenty-five years, predominantly with no government support. In the coming years it is increasingly inevitable that many State Networks will cease to function as ageing polio volunteers are unable to continue their efforts. In recognition of this, Polio Australia was established by the State Networks in 2008 as the national voice for polio survivors to carry forward the battle for recognition of, and assistance for, the LEOP.

The needs of polio survivors have been largely neglected since vaccination against the disease became a reality, but as they age with a chronic disability this neglect must be redressed as a matter of urgency. The time has now come for the Government to reduce the burden on ageing volunteers and support polio survivors nationally through Polio Australia's effective programs.

Case study – *“The Polio Network made me realise I was not going mad when doctors could not explain why I felt so bad. I now have greater understanding which has relieved my stress levels considerably.”*

Case study – *“For most of my life I just got on with it. Now I am finding the information about polio and the way it has affected me in later years very useful for helping me maintain my independence.”*

See Recommendations 1, 10, 11, 14, 18

5.3 The special needs of people from culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander (ATSI) communities

Issue:

State Polio Networks and their respective support groups have identified an under-representation of CALD and ATSI members accessing existing polio support services. Furthermore, there is no Polio Network in the Northern Territory and younger polio survivors are from CALD communities.

See Recommendations 15, 16, 17, 18

6. SUPPORT AVAILABLE TO POLIO SURVIVORS FROM CURRENT INITIATIVES

6.1 The National Disability Agreement (NDA) The following three examples show major gaps:

a) *“Services Planning and Strategies to Simplify Access – A National Framework for Service Planning and Access will focus on providing a person centred approach to service delivery and simplify access to specialist disability services”.*

Issue: The two small ‘specialist disability services’ for polio survivors in Victoria and WA are chronically under-funded and over-subscribed by polio survivors seeking specialist help.

See Recommendations 1, 2, 3, 7, 9

b) *“Early Intervention and Prevention, Lifelong Planning and Increasing Independence and Social Participation Strategies – a framework is currently under development to ensure clients receive the most appropriate and timely support and to increase Government’s ability to be effective with early intervention and prevention strategies”.*

Issue: This strategy cannot be effective for polio survivors until there are sufficient specialist services available to deliver *“appropriate and timely support”*. One small team at PSV, and volunteer support groups cannot begin to provide *“appropriate and timely support”*.

See Recommendations 1, 3, 7, 9, 10, 11

c) *“Improved Access to Disability Care – under this priority, systems will be developed to improve access to disability care, and to ensure people are referred to the most appropriate disability services and supports. This will include consideration of single access points and nationally consistent assessment processes in line with agreed principles”.*

Issue: Until strategically located specialist polio services are developed with the ability to manage the unique effects of LEOP this strategy cannot be achieved. Currently the small PSV team is the only *“appropriate disability service”*, along with the small team in WA.

See Recommendations 1, 3, 7, 9

6.2 The National Disability Strategy, a mechanism to ensure principles underpinning the United Nations Convention on the Rights of Persons with Disabilities are incorporated into policies and programs affecting people with disability. Point ‘O’ reads: *“Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them,”*

Issue: This fundamental area of the UN Convention has been compromised for polio survivors. Polio Australia has the mandate to represent Australia’s polio survivors and the State Polio Networks and has provided substantial evidence in proposals to Federal parliamentarians and the Department of Health and Ageing to demonstrate that the needs of polio survivors living with the LEOP are *not* being met.

See Recommendations 1, 7, 8, 9

6.3 The National Primary Health Care Strategy identifies *“better management of chronic conditions”* as one of four key priority areas.

Issue: People suffering from LEOP may be eligible for services through the Chronic Disease Management items on the Medicare Benefits Schedule which assists GPs to manage the health care of patients with chronic conditions, including patients needing multidisciplinary care. But *first GPs need to be taught* how to recognise, diagnose and manage LEOP complications.

See Recommendations 1, 2, 3, 4, 7, 9

6.4 The Medicare Benefits Schedule has the potential to benefit polio survivors.

Issue: No program will help people experiencing LEOP until GPs can recognise, diagnose and prescribe effective management tools for the unique and complex problems associated with LEOP.

See Recommendations 2, 4, 9

6.5 The Enhanced Primary Care Program is excellent for many people with chronic conditions.

Issue: The limit of five sessions a year is totally inadequate for polio survivors with complex, ongoing and deteriorating needs. LEOP can be productively managed with appropriate advice and strategies, *but* unlike some conditions, it cannot be 'cured'.

See Recommendation 4, 9

6.6 The National Health and Medical Research Council (NHMRC)

Issue: The 2009 Nutbeam Committee recommended *"That NHMRC facilitate the development of large scale, long term, and nationally relevant public health research infrastructure. This would include support for significant large cohort studies, diseases registers, data-linkage and survey facilities.* Polio Australia strongly supports the need to urgently establish a *"Polio Disease Register"* which can build on the volunteer work already initiated by Polio Australia.

See Recommendations 1, 9, 12, 13, 14

7. CONCLUSIONS

Polio survivors form the largest *single group* of people with physical disabilities in Australia, yet this has not been recognised by policy makers, the community at large, and indeed many polio survivors. Polio survivors are to a large extent *invisible* in the community and the late effects are rarely recognised by health professionals as a 'condition' which is capable of immense impact upon the lives of survivors and their families. **The large number of survivors now experiencing LEOP has transformed the problem from an individual predicament to a social concern.**

The Government has a strong focus on prevention, with an emphasis on primary care; cooperative endeavours between the Commonwealth, states and territories; and on measures that evidence health outcomes. Furthermore, management for chronic, long term conditions and their support services is an issue being considered in health reforms which the Government is keen to progress.

Polio Australia maintains that LEOP services will not improve until Polio Australia's program recommendations are implemented. **No matter how effective health system changes are, until the significant knowledge gaps in LEOP knowledge and management are addressed, appropriate and timely services for polio survivors will continue to be adversely impacted.**

Without the knowledge of what to look for when presented with disparate LEOP symptoms, GPs are unable to make an accurate diagnosis. Instead, treatment focuses on the most prevalent manifestation – usually muscle weakness and/or joint pain and 'diagnosis' of *'arthritis'* and/or the *'general effects of ageing'*. The patient is then referred to an equally unaware physiotherapist to *'build up muscle strength'* using inappropriate, rigorous exercise routines, which *exacerbate damage* to the already fragile motor neurons of a person experiencing LEOP. **This continued lack of awareness causes avoidable acute care incidents and a spiralling cost to Australia's health system.**

Many polio survivors who walked independently must now use braces, crutches or wheelchairs and make changes to their work and home lives which is often viewed as failure. Costs to the taxpayer of acute care episodes resulting from falls, for example, is significant. Survivors are increasingly forced to rely on family support, often ageing partners, to undertake daily living activities, risking further medical issues, such as back strain, depression and social isolation.

Case study – *"I had a breakdown 2 years ago from my GP's attitude. Now have a great GP."*

Polio Australia urges the Commonwealth Government to consider the recommendations in this paper *now*, to avoid increasing pressure on health, disability and aged care resources resulting from the lack of availability of services providing informed and timely intervention as polio survivors age with their unique chronic condition. It has been established elsewhere that for every \$1 put into prevention there are \$5 of savings. **Central to Polio Australia's recommendations is the development of a National Polio Strategy to establish as a national health priority the diagnosis and management of the LEOP and the ongoing support of polio survivors and their families.**

Case study – *"Knowledge (and wisdom) is powerful. Having learned to pace myself, my quality of life has improved immensely."*