



BREATHE SAFELY, LIVE WELL

Pilot Project

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1.1. Background to 'Breathe Safely, Live Well'

People living with the after effects of polio often have respiratory conditions which are not recognised by them, or by health professionals. This leads to difficulty in maintaining daily activities and responsibilities, as well as causing significant problems during anaesthesia and rehabilitation.

Development and implementation of a protocol is necessary to alert hospital staff to polio risk factors, as well as including recommendations to mitigate unwanted complications of respiratory decline, collapse and death.

Polio survivors need regular assessment and particular care during anaesthesia and recovery periods.

This is not happening in most Victorian and Australian hospitals. The resultant respiratory deterioration does cause reduced ability to cope with living in the community, caring for family members and employment. Untimely death obviously causes great distress to family and friends.

1.2 Project 'Breathe Safely, Live Well' Overview

The proposed project involves taking the early work done by St Vincent's Hospital Melbourne, developing it further, disseminating it throughout the Victorian health system before its' introduction into the Australian health system. The project involves working with the relevant professional associations and education authorities to help ensure that health providers are aware of and trained in dealing with approximately 150,000 people with polio, post polio syndrome or late effects of polio in Australia. Accurate statistics are unavailable⁷. People with other neurological conditions may also benefit.

1.3. Auspice

Post Polio Victoria will auspice the project 'Breathe Safely, Live well'.

Post Polio Victoria is an organisation of volunteers with expertise in polio. It was formed in 2011 and researches and advises on maintenance and development of adequate services, to enable full social participation, for survivors with physical, orthopaedic, respiratory, fatigue, pain and mobility impairments.

Post Polio Victoria's activities centre around

- Representing people with polio to levels of government, health systems and service providers
- Providing information to people with polio concerning provision of health services, government support and self management strategies



- Educating and raising awareness amongst health service providers and government about the health and support needs of people with polio .
- Development and dissemination of information is particularly important.

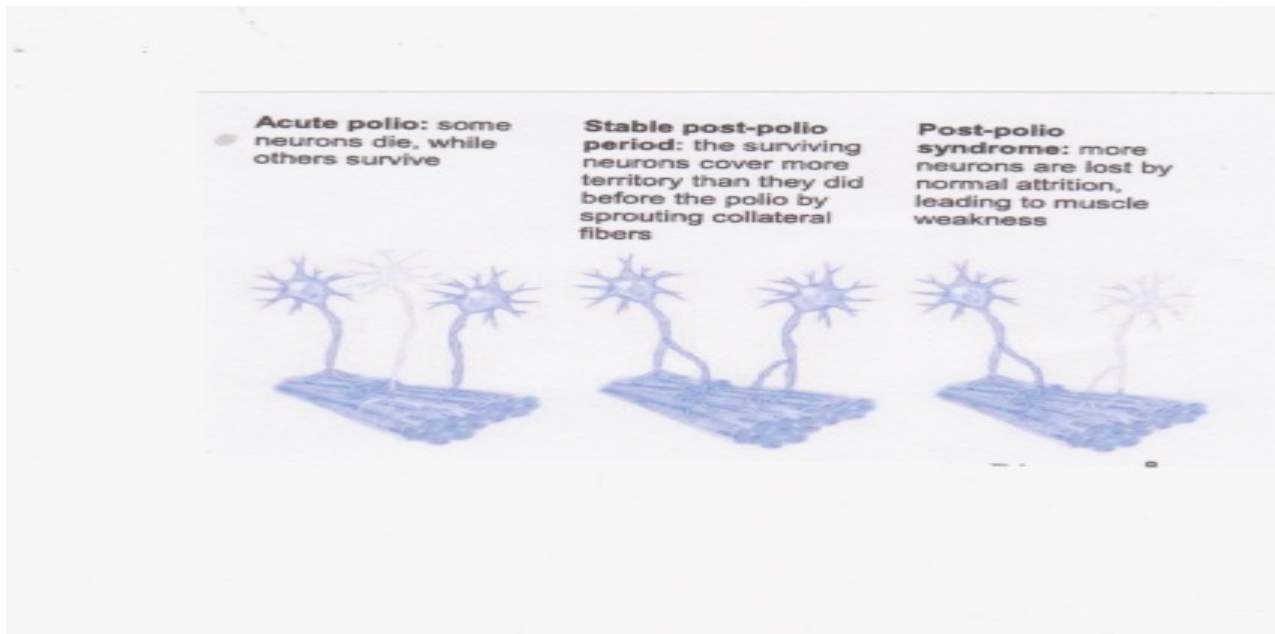
Post Polio Victoria has DGR status.

While focused on Victoria, we are involved with Polio Australia and liaise closely with our interstate equivalents and polio support groups in Victoria.

1.4. Polio

Polio is a notifiable viral disease fatal in 10% of cases ¹ where paralysis occurs, with mortality rates higher in adults ². Polio viruses destroy, forever, many spinal nerve cell connections with their muscle cells. The destruction is erratic so that paralysis is uneven and bones may become twisted leading to uneven joint wear. The diagram below demonstrates apparent partial recovery when an unaffected nerve cell connects to more than one muscle cell.

Post polio syndrome occurs when the over used nerve cell fails 40-60 years after polio occurs



An estimated 40-60% of survivors develop post polio syndrome ³ which includes respiratory dysfunction, ⁴ including sleep apnoea which is a factor associated with stroke occurrences, ⁸ as well as increased risks of failure during and after anaesthesia ⁵.

There are an estimated 70,000 ⁶ – 400,000 ⁷ survivors with polio in Australia with the majority living in the south-eastern states.



Those who have survived have developed full lives albeit with disability. This short film from Bayside Polio gives some indication

<https://www.youtube.com/watch?v=7YpfQQWHEVo&feature=youtu.be>

2. Project 'Breathe Safely, Live Well' Detail

2.1. Goal

Our goal is to have an alert, assessment and treatment protocol accepted and used by all hospital and rehabilitation systems.

2.2 Our objectives are to;

- Further develop a comprehensive literature review
- Work with St Vincent's and Austin hospitals to develop their alert protocols
- Work with the Victorian Health Care Association to enlist their members cooperation
- Work with Vic Health concerning education of health professionals
- Further develop information dissemination via Post Polio Victoria's website
- Consult with Polio Services Victoria about their inclusion in an assessment strategy

2.3. Project approach.

- Employment of a professional who has scientific knowledge, and who has the capacity to work with different sectors of the health system, to be the project officer.
- A reference group facilitated by Post Polio Victoria, and including representatives from relevant organisations, would share information, known literature and actively supervise/consult with the project officer.

2.4. Proposed Project stages.

- Stage 1.
Further develop a comprehensive literature review
- Stage 2.
Work with St Vincent's Hospital to develop their protocols further and engage with other public hospitals in similar policy building and implementation strategies
- Stage 3
Work with Polio Services Victoria and the Department of Health and Human Services on possible inclusion in an assessment strategy.

Polio Services Victoria has been funded, since 1998, by the Department of Human Services Ambulatory Care program to replace the services



formerly available through Fairfield Infectious Diseases Hospital. It is housed at St Vincent's Hospital. The funding enables the small, dedicated and expert staff to assess, prescribe, and refer to external service providers, a limited range of management strategies such as physiotherapy. A sessional rehabilitation doctor is required to authorise any action. Respiratory assessment is not provided and may not be considered in every patient's plan.

- Stage 4
Further develop information dissemination via Post Polio Victoria's website and other appropriate media
- Stage 5
Work with the Victorian Health Care Association to enlist their members Knowledge and cooperation
- Stage 6
Work with Vic Health concerning education of health professionals

3. Resources needed

1. The budget expenses are expected to total \$200,000.

Costs would be

- | | |
|--|-----------|
| • Salary for 1 year fulltime work
+ insurance & penalties for
after hours meetings | \$150,000 |
| • Travelling expenses | 20,000 |
| • Work space at Ross House | 6,500 |
| • Laptop & storage cabinet | 1,500 |
| • Phone & plan | 2,000 |

2. Available resources

At this time Post Polio Victoria has less than \$8,000 banked, no regular funding and relies on volunteers and donations.

Our resources lie in the skills and knowledge of our members and networks.

4. Evaluation Plan

1. An Evaluation Committee would be constituted of representatives of organisations relevant and external to Post Polio Victoria and two Post Polio Victoria committee members.
2. Evaluation would be of the achieved outcomes of Stages 1-6.



We would appreciate the opportunity to discuss this proposal and our goal and objectives further.

Geoff Dean

Margaret Cooper OAM, PhD

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