



Post Polio Victoria Inc.

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Dear Support at Home team

Post-Polio Victoria (PPV) is an advocacy and policy organisation that represents polio survivors from the 1950's epidemics. Now, many of us suffer with Post Polio Syndrome (PPS)/Late Effect of Polio (LEOP), a debilitating condition. Therefore, we are responding to the Assistive Technologies and Home Modifications Scheme.

For decades, we have lived with long-term disabilities, which increases with PPS/LEOP. Polio survivors from the 50's over 65, have been excluded from the NDIS. Yet, we need the assistive equipment, care, and home modifications that are allowed within the NDIS.

The My Aged Care system should provide such equipment, help and support based on individual needs to enable people to remain safely in their homes and integrated within their communities. Safety at home prevents long-term hospital stays, and admissions to nursing homes. This will save millions to the Annual Health Care Budgets of State and Federal Governments.

A **major problem** is the complexity of the current Commonwealth Home Support Package (CHSP), My Aged Care (MAC) and the National Disability Insurance Scheme (NDIS) and its' bureaucratic, multi-layered processes. These are supposed to achieve simple outcomes not requiring expensive bureaucratic involvement.

It should not be up to the patient to justify his/her need for a particular support e.g., a wheelchair, if a highly qualified doctor diagnoses the need. But, under the present scheme a medically unqualified bureaucrat (who has no lived experience of disability) has the authority to say yes or no.

The following scenario is an exemplar of an issue faced by a lady battling financially, physically and mentally to remain in her home in a dignified way.

"Robyn is a 72-year-old single, disabled, aged pensioner who will require a bathroom that allows her and the assisting carer to be able to shower, bathe, use a sink, and go to the toilet.

It begins with access to the room, which includes adequate doorway width, door swing or slide in an appropriate way to be safe. Also, a toilet of appropriate height

and ease of wheelchair transfer; shower accessibility and bath and sink. Minimal slip and draining floor surface for safety, most of which does not exist in Robyn's bathroom.

For this to happen we are not talking about minor modifications and rails but a significant bathroom renovation. Robyn's existing bathroom is good but limits access and ability for toilet transfer. She has shower accessibility, but cannot use the bath which may be necessary at times. Her sink is not accessible from a wheelchair.

This would not be a renovation, home improvement or upgrade, but, an alteration for safety. Her bathroom becomes a fit for purpose room allowing Robyn to stay at home, toileting and cleaning herself safely. It also ensures the safety of a helping carer.

*Her story is sad, protracted, and, undignified as she battles her disability and ageing, while My Aged Care (MAC) makes her save up for minor modifications which will not resolve her issues or help her. MAC and assisted technologies **must** assist Robyn and others to modify their bathrooms to allow dignified ageing, and so continue their contribution to family and society.*

Robyn should not have to argue, save and grovel for what is the right thing. After all she needs to go to the toilet and clean herself. Rails, etc do not do this."

We are concerned that the whole submission continues to wipe out disability. Everything is focussed on age. The childhood disabilities of polio survivors are ignored, as are our lived experiences, insights, and expectations. A system designed for non-disabled oldsters is irrelevant to people with long-standing disabilities.

Post-Polio Victoria is advocating for the safety and security of polio survivors, the provision of all equipment recommended by a health professional. This will save us, Governments, and, the Nation time, money, and energy; allowing us to live lives of dignity.

Please acknowledge receipt of this letter.

Yours

Shirley Glance OAM
President
Post Polio Victoria Inc.