

PARKINSON'S VICTORIA SERVICES ARE AT RISK - WE NEED YOUR HELP

Parkinson's Victoria relies heavily on Victorian Government funding to deliver essential services tailored to the Parkinson's community – a health information line, peer activities, development and delivery of Parkinson's education and research translation.

Our community encompasses those living with Parkinson's, Atypical Parkinson's such as Progressive Supranuclear Palsy (PSP), Cortical Basal Syndrome (CBS), Multiple System Atrophy (MSA) and all other Parkinsonism's.

However, we have been advised that in July 2019, our Victorian Government funding will cease. Unfortunately, our approaches to the Minister for Health, Jill Hennessy, have so far been unsuccessful.

So we now call on you, our friends of Parkinson's Victoria, to support us as we lobby the Victorian Government (and Opposition) to ensure there are no cuts to this vital service.

2018 Victorian Government Election Campaign

The Victorian election will take place in November 2018. Soon we will start to see discussions about key issues in the media, between candidates and within the community. This is the time for constituents (members of the public) to share their opinions about what matters most to them.

We call on you to support us by starting the conversation with your local Member of Parliament (MP) to raise awareness of the impacts of Parkinson's and why ongoing funding of our services is critical.

We are campaigning so the Victorian Government continues to fund Parkinson's Victoria to ensure people with Parkinson's and their families continue to:

- receive tailored health information to support them on their journey
- receive education that builds their capacity to manage their symptoms and understand treatments
- feel connected in the community
- have access to services and supports from the health, aged and disability sectors that meet and are responsive to their needs.

Parkinson's Victoria is committed to ensuring the needs of people living with Parkinson's, and all those who care for them, are heard. We are meeting with key government Ministers, MPs, candidates and community partners to lobby for ongoing funding for our organisation and the community we support.

However, we know that individuals can have a powerful influence on Government. That is why we encourage you to join our campaign and advocate for the rights of people living with Parkinson's.

How can I help?

We ask you to consider contributing to this campaign by arranging to meet with your local MP. You can use the information in this document to guide you on how to contact your local MP to arrange a meeting.

What issues should I discuss when campaigning?

Having a united voice is important; that way everyone supporting this campaign shares common messages and information. So, we ask you to reflect on the key issues that Parkinson's Victoria is campaigning on and relate them to your situation.

One of the most powerful ways to gain the attention of MPs is to share your personal story of Parkinson's. But before you do so, consider whether you want your story to be shared publicly.

That is because a MP can raise constituent's concerns in Parliament. If you want to protect your privacy (eg, tell your story but keep your name private), you need to advise the MP and their staff.

Key issues you may want to discuss:

- your Parkinson's experience
- how Parkinson's has affected your life
- how Parkinson's Victoria has supported you
- how your situation could be improved
- what impact the withdrawal of Parkinson's Victoria services will have on you.

How should I approach my Member of Parliament?

The Victorian Government now makes it as easy as possible for community members to get in touch with MPs in the Upper and Lower Houses, as well as Ministers and Shadow Ministers.

You can find local MPs' names, contact details, biographies and ways to get in touch with them by conducting a member search - www.parliament.vic.gov.au/about/people-in-parliament/members-search/search-members

If you are having any difficulty identifying who you should contact, get in touch with Parkinson's Victoria and we can assist you.

How do I request a meeting?

You can request a meeting by calling the MP's electorate office – the staff member will ask the purpose of your meeting and try and find a time that best suits you all.

Remember that politicians are often very busy – so the earlier you can arrange a meeting the better.

How should I prepare for my meeting?

Remember this is a chance for your local MP to be across local issues.

Ways of preparing for your meeting:

- You may want to bring someone with you, but be sure to let electorate staff know of this in advance.
- Usually you will only have 15 minutes for your meeting, so it is a good idea to go into it with dot-points of the key issues you would like to discuss.
- Arrive to your meeting at least 10 minutes early and be sure to turn off your mobile phone.
- Thank the local MP for taking the time to meet with you and comment on any good work you feel he/she has done for the community.
- Introduce your experience with Parkinson's, how it has impacted you and your family and what you feel needs to be done to ensure ongoing support for the Parkinson's community in Victoria.
- Refer to the key statistical information (attached) that Parkinson's Victoria is campaigning for and how addressing these are positive for you, your family and others with Parkinson's.
- Outline why you are concerned that funding for Parkinson's Victoria is not confirmed beyond July 2019 and what could happen if funding is taken away.
- Ask your local Member to bring these issues to the attention of the Premier Daniel Andrews, Deputy Premier James Merlino and the Leader of the Opposition Matthew Guy.
- Ask your local MP to raise this issue at their Party Meetings and with the Minister for Health Jill Hennessy and Shadow Minister for Health Mary Wooldridge and to let you know their response (it is vital to leave the MP an action and reason to respond to you).
- Thank the person for their time and let them know they are welcome to contact Parkinson's Victoria's CEO Emma Collin for further information about Parkinson's issues in Victoria.
- Write a letter or email to formally thank the MP for their time and reiterate any commitments discussed during the meeting and your expectation for them to contact you following a response from the Minister/ Shadow Minister.

How can Parkinson's Victoria assist me?

Parkinson's Victoria is truly appreciative of your support for us – so we are keen to support you!

If you have any questions about this campaign or to confirm your willingness to participate in the campaign, call (03) 8809 0400 or email info@parkinsons-vic.org.au.

We would also like to hear from you after your meeting with your MP. Please email feedback to info@parkinsons-vic.org.au.

Parkinson's information

The impact of Parkinson's including the Atypical Parkinson's conditions - Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortical Basal Disease (CBD) - and the demand for support services and programs is very real. For those living with Parkinson's, their families and friends, the impact of this funding withdrawal is huge.

Parkinson's - key statistics

- Of the 80,000 Australians living with Parkinson's, it is estimated that 27,000 live in Victoria.
- Of those Victorians, 82% are over the age of 65 years.
- There are an estimated 4000 Australians living with the Atypical Parkinson's conditions, 1000 of whom live in Victoria
- Young Onset Parkinson's impacts 18% or approximately 5000 Victorians.
- Living with Parkinson's can greatly affect a person's employment and independence. It also impacts on the lives of those who care for a person living with Parkinson's.
- Around 40% of people with Parkinson's also live with depression and anxiety.

Parkinson's Victoria– lack of funding impacts

Loss of Victorian Government funding in 2019 will mean:

- Parkinson's Victoria will not have the resources to support the development and tailored delivery of quality Parkinson's information, which plays a crucial role in ensuring people with Parkinson's are managing their symptoms and accessing appropriate services and supports to meet their unique needs.
- Parkinson's Victoria will not have the resources to support the development and delivery of specialised education programs to people living with Parkinson's, PSP, MSA, CBD, Health Care Professionals and Residential Aged Care Providers.
- Families and carers will not receive information or education about Parkinson's or know who to turn to in order to support the specific needs of the person they are caring for.
- People living with Parkinson's will become more isolated in their community; they will not know how to connect to specialised supports, community services or support groups (such as peer support, psychological or other allied health supports).
- Increased accident and emergency (A&E) presentations and hospital admissions will occur due to a lack of education and training in the community and a reduction in specialised knowledge of Parkinson's in all first responders, GPs, health professionals and aged care workers.
- Less than 1% of those diagnosed with Parkinson's under the age of 65 years will be able to access the NDIS, with the remaining 99% not able to seek support from Parkinson's Victoria.
- Parkinson's Victoria will not have insurance cover, currently provided through DHHS, for 64 peer support groups, community events and activities.
- The impact of reducing Parkinson's Victoria's service delivery will be substantial for the Victorian economy as a result of increased demand on the health and education systems and reduced contribution to society.

What is at risk?

In 2017-18, Parkinson's Victoria provided a range of programs and services which are at risk.

They are:

- Specialist information services, including the support of our multidisciplinary team for 4685 tele-health calls per annum, and maintenance of our web-based information services for 115,717 unique users.
- Coordination and provision of support and insurance for our 64 Peer Support Group across rural, regional and metropolitan Melbourne - supporting 3019 people living with Parkinson's.
- Professional education services including delivery of our recently diagnosed seminars, research lectures, living well seminars, community and Atypical Parkinson's seminars and education sessions for GPs and healthcare professionals - supporting 2980 attendees.
- Insurance for our key community awareness raising events including A Walk in the Park – which attracts 4000 participants in Melbourne and regional sites at Geelong, Bendigo, Mildura, Horsham, Timboon, Warrnambool, Wodonga and Yarrawonga.

Without Parkinson's Victoria, delivery of these vital, tailored information and education services will fall to the already overburdened Health System, while the community peer support program is at risk of ceasing altogether.