

# A CALL TO ACTION IN PARKINSON'S



Priorities to improve the lives of  
those affected by a common, yet  
poorly understood degenerative  
neurological condition in Australia

## **The Parkinson's Collaborative Group**

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This project is an initiative of AbbVie Pty Ltd. It should be noted that whilst AbbVie were the funders of the *A Call to Action in Parkinson's*, the content was shaped and determined by the Parkinson's Collaborative Group (PCG), under the independent and *pro bono* leadership of A/Profs Fung and Kimber.

## FOREWORD

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Ms Ann Sudmalis MP

Chair, Parliamentary Friends of Parkinson's

Parkinson's is a progressive neurological disease that takes an enormous toll on the people living with the condition, their loved ones and those who care for them. Even with a number of treatment advancements and improvements in services in recent years, Australians with Parkinson's still face a number of challenges. These people need, and should be able, to access high quality healthcare, social care and access to support services, no matter where they live in Australia.

The Friends of Parkinson's group was reconvened in 2013 to highlight Parkinson's issues within Parliament and attempt to address and raise awareness of any barriers that exist which prevent Australians with Parkinson's from living well with this disease.

As the Chair of the Parliamentary Friends of Parkinson's, I welcome this report and commend the multidisciplinary team of people behind the Parkinson's Collaborative Group. Bringing attention to this progressive, debilitating condition and what needs to be done to improve outcomes for Australians impacted by Parkinson's is a critical next step to improve the lives of those affected. Contained in this report is consensus for a clear, actionable national plan to improve care for Australians living with Parkinson's disease. This report represents the views of health professionals, people living with Parkinson's and the people involved across the entire continuum of care.

A handwritten signature in black ink, reading 'Ann Sudmalis' in a cursive script.

Ann Sudmalis MP

## A MESSAGE FROM THE CO-CHAIRS

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Parkinson's is a condition that affects tens of thousands of Australians. In addition to its physical manifestations, Parkinson's commonly has significant impacts on a person's emotional and cognitive wellbeing, as well as on their social functioning and ability to work. It is a condition that impacts not just the person with the illness, but all those who care for them.

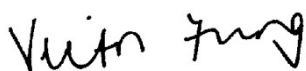
Despite this, Parkinson's has in many respects been a "hidden" disease in our community and health care system, with a public and political profile far below that afforded other important health problems.

The Parkinson's Collaborative Group consists of a small number of experts in the field of Parkinson's, encompassing medical, nursing, allied health and health advocacy. The group has drawn on information from many sources about the perceived needs and shortfalls in services for people with Parkinson's in our community. The "Call to Action in Parkinson's Disease" is the result of that work.

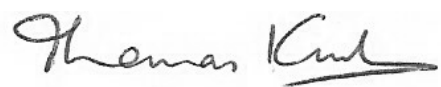
This document has been intentionally titled "A Call to Action". People with Parkinson's are living with us everywhere in the community, but the majority lack access to appropriate care due to geographical and financial constraints that impact on the health services available. In response, we have developed pragmatic recommendations to improve the delivery of care for today's people with Parkinson's, which are imminently achievable with policy and budgetary support from Federal and State Health Departments.

We eagerly await Governments' responses to this call, to enable us to work together to improve the lives of the many thousands of Australians affected by this devastating condition.

We extend our thanks to all participants in the process thus far, and we sincerely hope that the "Call to Action" will provide a catalyst for positive change in the way people with Parkinson's are supported and cared for in Australia in the very near future.



Associate Professor Victor Fung



Associate Professor Thomas Kimber

## INTRODUCTION

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Despite recent advances in the management of Parkinson's, a significant number of challenges remain.

Around 80,000 Australians are estimated to have a diagnosis of Parkinson's and more than 30 people are diagnosed daily – a prevalence exceeded only by dementia in terms of neurological conditions (Better Health Channel 2015; Deloitte Access Economics 2011; Parkinson's Australia 2013).

People with Parkinson's experience significant disability and require increased levels of care as their disease progresses. A 2007 Access Economics report found that living with Parkinson's is more burdensome than blindness or deafness in the initial stages, is on par with severe depression in the intermediate stages, and in the final stages is on par with terminal cancer or severe dementia (Access Economics 2007).

A key concern among health professionals involved in the management of people with Parkinson's is the reality of the patient experience of care – there are perceived gaps in patient services and some services are difficult to access.

With an ageing population, the numbers of newly diagnosed people with Parkinson's disease will continue to grow steadily, placing a greater urgency on the need to improve the recognition, diagnosis and management of the disease in Australia (Deloitte Access Economics 2011).

In response to these challenges, the Parkinson's Collaborative Group (PCG), an initiative of AbbVie Pty Ltd, was formed. Co-Chaired by Movement Disorders Specialists Associate Professor Victor Fung (Westmead Hospital) and Associate Professor Thomas Kimber (Royal Adelaide Hospital), the PCG consists of a diverse group of stakeholders with an interest in Parkinson's disease, who are united in their desire to establish a shared agenda for taking action to improve the lives of all those affected.

*A Call to Action in Parkinson's* is the result of this collaboration. It represents a positive step forward in shaping care for Parkinson's in Australia. It defines a viable action plan, whilst recognising the important work being undertaken by Parkinson's Australia and the related State and Territory organisations, along with the many committed healthcare professionals and community organisations with an interest in Parkinson's, those directly affected by Parkinson's and their carers.

## WHY DO WE NEED A CALL TO ACTION?

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A World Health Organisation (WHO 2006) report has found Parkinson's to be one of the most difficult neurological disorders for healthcare professionals to manage, due to the degenerative nature of the disease and the complicated and diverse associated symptoms (motor and non-motor).

To navigate the often complex challenges of managing a person with Parkinson's, particularly as their disease and associated symptoms progress, a multidisciplinary team of healthcare professionals and community support services is required (Hayes et al 2010).

In Australia, Parkinson's is the most common neurological condition after dementia, and the number of people being diagnosed with the disease is increasing. Around 80,000 Australians are estimated to have a diagnosis of Parkinson's and more than 30 people are diagnosed daily (Better Health Channel 2015; Deloitte Access Economics 2011). By 2031, it is estimated that this figure will grow to 115,300 people living with Parkinson's in Australia (Deloitte Access Economics 2011).

As the number of Australians affected by Parkinson's continues to grow, so too does the need for a multidisciplinary team of healthcare professionals who are properly trained to support their unique needs (Hayes et al 2010).

In Australia, advocacy efforts to improve the care of Parkinson's are gaining force. In a recent policy paper (Parkinson's Australia 2014), Parkinson's Australia say current Federal Government policy fails to address the needs and requirements of people with Parkinson's in spite of the prevalence and management challenges, and have called for an urgent public policy response.

With the release of the 2015–16 Federal Budget and the reform agenda of the current Government, particularly in relation to the Health system, opportunities exist to provide input into these discussions, to help shape the delivery of care for the benefit of people with Parkinson's disease in Australia. This requires a focused effort and a pragmatic approach.

## IDENTIFYING THE CORE CHALLENGES AND THE WAY FORWARD

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To ensure a broad range of views were considered, qualitative interviews were conducted with people from a variety of backgrounds, including healthcare professionals with an interest in Parkinson's, related advocacy organisations and people with Parkinson's and their carers (see Appendix for further details).

Through this consultation process, the following core challenges in Parkinson's in Australia were identified:

### **Non-motor symptoms of Parkinson's disease are poorly understood by the community and many healthcare professionals**

- Whilst there is a general level of awareness of Parkinson's, partly driven by high-profile individuals with Parkinson's who have a visible tremor (e.g. Michael J Fox, Mohammed Ali), there appears to be limited knowledge of non-motor symptoms amongst the community.
  - This may mean individuals experiencing non-motor symptoms may not present to their doctor to discuss these issues until later in their disease course, delaying diagnosis.
- Primary care physicians may not consider Parkinson's in those with atypical disease presentation (e.g. displaying non-motor symptoms), also delaying diagnosis
  - This can be compounded by the current lack of a simple and accurate diagnostic test for Parkinson's.

### **Parkinson's is commonly considered a disease that tends to affect older people**

- While Parkinson's is more common in older individuals, about 1 in 25 patients are less than 50 years of age at the time of diagnosis.
- Those with younger-onset disease may not think their symptoms are a concern as they don't consider themselves to be in the age group that is likely to have Parkinson's, and therefore don't present to the doctor.
- Specific information for people with younger-onset Parkinson's is limited in Australia.

### **The number of healthcare professionals with expertise in Parkinson's appears to vary greatly depending on geographical location**

- Access to healthcare professionals with expertise in the management of Parkinson's (across professions) varies depending on geographical location which can impact on timely diagnosis and/or optimal ongoing care, particularly for those who live outside of metropolitan areas.
- Where suitable support services (e.g. physiotherapists with expertise in Parkinson's) do exist, they can be difficult to locate, unless they are part of a Movement Disorder Clinic or a well-established local area network.

**People with Parkinson's want and need practical support to manage a range of issues related to their disease**

- This may include support for psychosocial issues or financial assistance (due to having to stop or reduce work), but can also involve the navigation of symptoms and day-to-day issues with medication.
- Nurses experienced with the condition are best placed to support people with Parkinson's with these daily challenges; however there are currently not enough such nurses in Australia.

When considering the ideal management approach for Parkinson's in Australia, the following was highlighted by stakeholders during the consultation process:

- Improving awareness and understanding of the non-motor symptoms of Parkinson's amongst the community and healthcare professionals will help support timelier diagnosis.
- A multidisciplinary team approach to the management of Parkinson's is the optimal care model, led by a central care coordinator (i.e. a Parkinson's nurse specialist). However:
  - Greater insight into the location of the current healthcare professional workforce with expertise in Parkinson's and the quality of care provided is needed to guide effective resource allocation.
  - A flexible, multidisciplinary, team-based care model that can be tailored to the needs of the patient and the availability of suitably trained healthcare professionals is key to improve the standard of care in Australia.
  - Positive examples of flexible multidisciplinary team-based care models exist in certain locations in Australia and internationally which can be utilised to create an optimal model in Australia with national reach.
- Supporting self-management and providing guidance on support services best suited to those affected by Parkinson's will help improve their experience and help delay progression into residential care.



## DEFINING AN ACTION PLAN

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In response to these challenges, the Parkinson's Collaborative Group convened a Roundtable meeting to review the insights gained through the consultation process and define a core set of priorities to improve the experience and management of people with Parkinson's disease in Australia.

These were the agreed priority areas:

**1. Increase the availability of quality information on Parkinson's disease for patients and healthcare professionals**

**2. Better understand the availability and quality of Parkinson's care across the country to help inform resource allocation**

**3. Expand access to specialised multidisciplinary care for people with Parkinson's**

**4. Develop a training model for Parkinson's nurses to support optimal multidisciplinary care and provide practical support**

## PUTTING AN ACTION PLAN INTO PLACE

### **PRIORITY 1:** **Increase the availability of quality information on Parkinson's disease in Australia**

#### **Rationale:**

As outlined in the National Chronic Disease Strategy, those with chronic health conditions need to be able to make informed decisions about their health, as evidence suggests that involving them in decisions regarding their care can lead to better health outcomes (NHPAC 2005; Bloem et al 2015).

A recent international survey of people with Parkinson's shows they have a strong desire to be involved in shared decision making (Bloem et al 2015). Having access to quality information about Parkinson's is therefore fundamental and aligns with a key insight identified through the consultation process – the need to increase the availability of quality information on Parkinson's. Whilst a range of communication channels can be utilised to achieve this goal, the online environment provides a clear opportunity.

Over 75 per cent of Australians over 50 access the internet daily and 87 per cent of Australians between 50 and 64 use Facebook around 20 times per week (Sensis 2015). Additionally, eight in ten internet users look online for health information with 56 per cent of internet users searching for information about certain medical treatments or procedures (Pew 2011).

#### **Actions:**

To support the goal of increasing the availability of quality information on Parkinson's in Australia, the Parkinson's Collaborative Group will:

- Collate best practice resources from Australian and internationally, including content provided by:
  - International Movement Disorder Society website
  - Parkinson's Australia (and related State and Territory organisations)
  - Shake It Up Foundation
  - American Parkinson Disease Association
  - European Parkinson's Disease Association
  - National Parkinson's Foundation
  - Davis Phinney Foundation
  - Center for Neurorehabilitation at Boston University
- Establish an online hub to link to existing quality information sources on Parkinson's that are relevant for Australian audiences.
- Work with suitable partners to seek endorsement of the online information hub.

**The Parkinson's Collaborative Group commits to producing an online resource in 2015 which provides links to quality information resources on Parkinson's for the community and healthcare professionals to support better understanding and improved management of Parkinson's in Australia.**

**PRIORITY 2:**  
**Better understand the availability and quality of Parkinson's care in Australia**

**Rationale:**

Anecdotal feedback gained through the consultation process indicates a disparity in the availability of healthcare professionals and support services for people with Parkinson's in various parts of Australia.

Whilst peer-reviewed published evidence is limited on the subject, a number of reports and articles in health industry publications exist to support this viewpoint (Duncan et al 2011; Giles et al 2008; Larter 2014; Noone 2014; Parkinson's Australia 2014).

To support advocacy efforts with the Federal Government there is a need to quantify this viewpoint with appropriate data, including identifying the areas of greatest need to improve the availability and quality of care for people with Parkinson's.

**Actions:**

To support the goal of better understanding the availability and quality of Parkinson's care in Australia, the Parkinson's Collaborative Group will:

- Use the European Parkinson's Disease Standard of Care Consensus Statement (EPDA 2011) and the Move For Change III European survey (Bloem et al 2015) as the basis for an audit of the care that people with Parkinson's in Australia are currently able to access and the quality of their experiences.
- Collate the evidence gained through the audit into a report which quantifies inequities in access and/or quality of care to encourage policy makers to invest in better services for people with Parkinson's disease in core areas of unmet need.

**The Parkinson's Collaborative Group commits to producing evidence to quantify the currently available healthcare services for people with Parkinson's in Australia to support advocacy efforts with the Federal Government to increase resource allocation for Parkinson's disease in areas of greatest need.**

### **PRIORITY 3:**

#### **Expand access to specialised multidisciplinary care for people with Parkinson's**

##### **Rationale:**

The promotion of a patient centred self-management model of care (Giroux et al 2008) and timely interventions rather than crisis management (Martin et al 2013) is central to best practice management of Parkinson's.

In order for self-management to be effective, people need to be able to make informed decisions about their health and have access to care planning and medication management (NHPAC 2005).

##### **Actions:**

The Parkinson's Collaborative Group will support the stepwise development of a "hub and spoke" style multidisciplinary model of care for people with Parkinson's disease in Australia which involves:

- Centres of Excellence in key metropolitan and regional hospitals that have a specialist Movement Disorders / Parkinson's disease multidisciplinary team onsite (HUB).
- Community-based care services with the knowledge and skills to support people with Parkinson's, combining physical and virtual support (i.e. telehealth) dependent on the location and availability of healthcare professionals (specialists and allied health) (SPOKE).

The critical steps to achieve this hub and spoke model of care include:

- Establishment of a national network of Parkinson's nurses (care coordinators) who can form the link between patients in communities and medical, mental health and allied health expertise and care at every stage of the illness.
- The identification of a national and systematic funding source for a network of Parkinson's nurses by:
  - Putting a submission into the Medicare Benefits Schedule (MBS) review to consider the extension of existing MBS item numbers currently utilised by allied healthcare professionals in chronic care to cover services delivered by specialist Parkinson's nurses.
  - Ensuring the appropriate accreditation is sought by Parkinson's nurses to enable use of MBS item numbers.
- Making a submission to the Parliamentary inquiry into Chronic Disease Prevention and Management in Primary Health Care showcasing examples of best practice in Parkinson's disease management using the multidisciplinary care model.

**The Parkinson's Collaborative Group commits to increasing recognition of the value of a multidisciplinary team approach to Parkinson's disease with Federal Government as part of the Health reform agenda and supporting the identification of a viable national and systematic funding source to support Parkinson's nurses in Australia.**

#### **PRIORITY 4:**

#### **Develop a training model for Parkinson's nurses to support optimal care**

##### **Rationale:**

People with Parkinson's should have access to a knowledgeable multidisciplinary team (Kale 2004), of which a key member is a Parkinson's nurse specialist.

The Parkinson's nurse specialist has the expertise and knowledge to educate and help people with Parkinson's and their families with the management of often complex medication regimes, thus improving their quality of life (O'Maley et al 2005) and facilitating self-management.

In instances where there are Parkinson's nurse specialists, the increase in health costs has been lower than those in a control group (Hurwitz et al 2005). Participants of the study who had access to a nurse had an improved sense of well-being.

In Australia, there are around 30 nurses who work specifically with people with Parkinson's and this number needs to grow urgently. Providing educational resources to upskill nurses is one important element to facilitate this.

##### **Actions:**

The Parkinson's Collaborative Group will help address the need to expand the current pool of Parkinson's nurse specialist through the following steps:

- Review existing nurse training modules for Parkinson's disease to develop a best practice training module in Parkinson's for nurses.
- Establish a partnership with an accredited training partner to finalise the Parkinson's disease specialist nurse training module.
  - This may include the Australasian Neuroscience Nurses Association and the Australian College of Nursing.
- Implement an accredited training module with agreed partners to support optimal continuity of care for people with Parkinson's disease in Australia.

**The Parkinson's Collaborative Group commits to supporting the expansion of Parkinson's specialist nurses in Australia by developing a best practice, accredited training module in 2015-16.**

### About A Call to Action in Parkinson's

The Parkinson's Collaborative Group (PCG) was formed to address the challenges faced by those with Parkinson's disease in Australia. Co-Chaired by Movement Disorders Specialists Associate Professor Victor Fung (Westmead Hospital) and Associate Professor Tom Kimber (Royal Adelaide Hospital), the PCG consists of a diverse group of stakeholders with an interest in Parkinson's, who wish to establish a shared agenda for taking action to improve the lives of all those affected. *A Call to Action in Parkinson's* is the result of this activity.

This project is an initiative and funded by AbbVie Pty Ltd. It should be noted that whilst AbbVie were the initiators of the *A Call to Action in Parkinson's*, the content was shaped and determined by the PCG, under the independent and pro bono leadership of A/Profs Fung and Kimber.

### Developing the Call to Action

To ensure a broad range of perspectives were considered in the development of *A Call to Action in Parkinson's*, interviews were conducted with stakeholders with a special interest in Parkinson's. This included a variety of healthcare professionals, advocacy organisations, people with Parkinson's and their carers.

These individuals included:

Type	Name	State	Location	Affiliation
Specialist	A/Prof Victor Fung	NSW	Sydney	Westmead Hospital
Specialist	A/Prof Thomas Kimber	SA	Adelaide	Royal Adelaide
Specialist	A/Prof Simon Lewis	NSW	Sydney	Brain Bank
Specialist	Professor Robert Iansek	VIC	Melbourne	Monash University
Specialist	Dr Michael Hayes	NSW	Sydney	Concord Hospital
Nurse	Evelyn Collins	NSW	Newcastle	John Hunter Hospital
Nurse	Sue Varley	VIC	Melbourne	The Alfred
Nurse	Kathy McCoy	WA	Perth	Neurological Nurses WA
Nurse	Jane Griffith	NSW	Sydney	Westmead Hospital
Nurse	Sheree Ambrosini	VIC	Shepparton	Goulburn Valley Health
Nurse	Sally-Anne Wherry	ACT	Canberra	Registered Nurse
Physio	Professor Meg Morris	VIC	Melbourne	La Trobe University
Physio	Colleen Canning	NSW	Sydney	University of Sydney
Psychologist	Prof Narelle Warren	VIC	Melbourne	Monash University
Patient	J.P.	NSW	Newcastle	N/A
Patient	G.P.	WA	Perth	N/A
Carer	N.P.	WA	Perth	N/A

Type	Name	State	Location	Affiliation
Professional body	Gordon Gregory	ACT	Canberra	National Rural Health Alliance
Professional body	Chris Shipway	NSW	Sydney	Agency Clinical Information (ACI)
Advocacy	Ben Young	NSW	Sydney	Shake It Up Foundation

To elicit qualitative feedback, a combination of open-ended and probing questions covered the following themes: Pathway to diagnosis, management of Parkinson's, access to services and support, experience in metropolitan versus regional settings, patient and carer engagement in care, optimal management of Parkinson's, personal impact of living with Parkinson's and suggested activities to improve the management of Parkinson's and the overall personal experience.

### About AbbVie

AbbVie is a biopharmaceutical company focused on developing new products and new ways to help people manage their health, and lead better lives. We tackle diseases where there is a significant need for more and better solutions. In Parkinson's disease our goal is to support individualised care for people whose disease has progressed to a point where motor symptoms are impacting on independence and quality of life despite optimised treatment. We work in partnership with everyone from health care providers to health consumer organisations, government and local communities to deliver on our commitment to ensure Australians with Parkinson's have access to innovative treatments and quality health care.

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Last updated: February, 2016.





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when you can't hold your camera steady."**

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