



Response to the Tasmanian Government's Discussion Paper

20 Year Preventative Health Strategy

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1 Executive Summary

Parkinson's is the fastest growing neurological condition in the world. An urgent public health response is needed to prevent the onset of Parkinson's in Tasmania, given the increasing prevalence of the condition and the demographics in Tasmania that will have significant economic, social and cultural impacts. Parkinson's currently costs the State government an estimated \$165 million per year, with this estimate expected to double by 2040. Available evidence indicates that Tasmania has the highest number of people living with Parkinson's in all of Australia.

Parkinson's is a condition that is extremely challenging to manage due to its chronic and progressive nature, as well as complicated and diverse physical and cognitive symptoms that creates variability. This is why the term "Parkinson's Disease" is not used, as it infers a single condition or set of symptoms, whereas it is impossible to define Parkinson's homogenously across the cohort. For someone living with Parkinson's in Australia, the cost for the individual to manage the condition is estimated to be around \$15,000 per year. This does not consider the loss or reduction income due to the progressive nature of the condition. It also does not factor in the loss of income for the carer.

There are markers of prevalence and risk factors for Parkinson's, but with no absolute cause, there is no cure. Prevention of the onset, via factors that are known, is therefore critical. Parkinson's has higher rates of onset than other neuro degenerative conditions, including Multiple Sclerosis (MS) and Motor Neurone Disease (MND).

Tasmania is a nation-leader in the quality of research being undertaken at the University of Tasmania (including the Menzies Institute for Medical Research, Wicking Institute for Dementia Research, and the School of Health and Medicine), a strong local voice, and expertise that brings a national and international profile (via Parkinson's Tasmania, Wings 4 Parkinson's, Tasmanian Parkinson's Project, and the Massive Open Online Course (MOOC)). Professor Michele Callisaya has recently secured \$3m in funding from the Federal Government for the ParkinsonNet research project. ParkinsonNET is based on the successful model of care in the Netherlands and is currently being implemented in Germany and Poland. Parkinson's Tasmania is working in partnership with Professor Callisaya to progress this project and will help to facilitate a pilot in Tasmania of the outcomes in the next 3-5 years.

A member of the cohort, Professor Jane Alty, has noted: *"A decade ago, we didn't think we could prevent dementia"*. Now, dementia prevention is an accepted strategy. The same is possible for Parkinson's.

Tasmania has the right elements to further lead the way in Parkinson's detection, prevention, and care:

- **One University:** UTAS brings together leading neuroscience research, enabling rapid coordination across disciplines and nationally significant research capacity with the *Wicking Dementia Centre*, and *Menzies Institute for Medical Research*.
- **Ageing Population:** Tasmania has the oldest demographic profile in Australia, increasing both the urgency and relevance of focused interventions.
- **Small Size:** Our size allows us to pilot, prove and scale initiatives faster than anywhere else.
- **Collaborative Cohort:** Key stakeholders, health professionals and nation-leading research community undertake collaboration in a way that could be described as "best practice".

The Tasmanian Government should take heed of the advice and contributions in this response to the Discussion Paper, and act intentionally in relation to prevention and risk reduction for Parkinson's. In the 20-Year Preventative Health Strategy, the following changes and initiatives need to be included:

1. Ban the pesticides (e.g. paraquat and chlorpyrifos) and chemicals (e.g. trichloroethylene) which have been linked to Parkinson's and develop safer alternatives as per World Health Organisation (WHO) guidance and in-line with other countries such as the USA and China.
2. Accelerate action to reduce levels of and exposure to air pollution, a risk factor for Parkinson's and other noncommunicable diseases, including Alzheimer disease, respiratory disease, heart disease and stroke.
3. Introduce a digital screening program that includes simple diagnostic tools and education on their use to people over 50 years old (parallel with bowel cancer screening).
4. Focus on the creation of multidisciplinary care models within the health system to focus on providing comprehensive and patient centred care. These models involve collaboration across healthcare providers to ensure that people with Parkinson's have access to a seamless and coordinated health care experience.
5. Introduce Parkinson's clinics and expertise centres. These centres bring together neurologists, physiotherapists and occupational therapists, speech therapists, psychologists and other specialists to offer holistic care. The model aims to improve diagnosis, treatment, and support for patients across the stages of progression.
6. Support public awareness campaigns – increase knowledge about the condition and promote early diagnosis. These campaigns aim to reduce stigma, inform the public about the symptoms and available treatments and encourage people to seek help early.
7. Enable and support Parkinson's Tasmania to be a sustainable organisation for people living with Parkinson's. Parkinson's Tasmania can be the coordination point and secretariat for other key stakeholder groups in the Parkinson's cohort and provide a centralised voice on policy and related matters. Navigating the complex health system is another gap that exists, and Parkinson's Tasmania could assist as a key enabler for the 20 Year Preventative Health Strategy.
8. Work with the Federal Government to pilot GP education for enabling early diagnosis of Parkinson's and ensure the same Parkinson's specific education is provided to other allied health professionals.
9. Introduce more Allied Health professionals trained in working with people who have neurological diseases, and more of them in rural areas. Ensure that they are delivering care according to guidelines, proactive from the time of diagnosis.
10. Introduce more neurologists.
11. Fund Critical Care Nurses that are trained and skilled in Parkinson's to prevent progression and functional decline, referring to both pharmacological and non-pharmacological interventions as the progress of the condition moves through all three stages (primary, secondary and tertiary).
12. Increase the promotion of healthy behaviour to the general population (e.g. exercise and diet) along the life-course to reduce the risk for Parkinson's and to enhance potentially protective factors.

13. Increase access to community exercise programs for people with Parkinson's, especially those with more severe disability (e.g. people who are having multiple falls may have difficulty and find it confronting to access a public gym and these facilities should be offering Parkinson's specific classes by trained coaches).
14. Invest in research initiatives to better understand Parkinson's, develop new treatments and improve patient outcomes. Collaborative research is supported by government agencies as well as private institutions and academic research centres to find new ways to slow disease progression and improve quality of life.

It is noted that videos and other materials were welcomed as part of a Discussion Paper response. The University of Tasmania's Massive Open Online Course (Parkinson's) is targeted at a public and health system audience and contains video reflections, research, information on prevention and the condition itself. Professor Jane Alty and Professor Michele Callisaya, who reside and work in Tasmania, developed the MOOC and have both contributed to this Discussion Paper response. The MOOC is being celebrated internationally and at the time of writing, with more than 20,000 people from 156 countries having completed it. It would be valuable to have the representatives of the Tasmanian Government drafting the 20-Year Preventative Health strategy undertake the MOOC, as it would provide invaluable context, data and other relevant information:

www.mooc.utas.edu.au/course/20278/Parkinson_s_MOOC_2025

Parkinson's Tasmania is uniquely positioned to contribute to the development and implementation of Tasmania's 20-Year Preventative Health Strategy. We understand the critical importance of early intervention, prevention, and sustained engagement in improving health outcomes for people living with Parkinson's. It is hoped that this response to the Discussion Paper is the start of a prioritised discussion, let alone action regarding a condition that impacts many Tasmanians and their families now and is set to materially increasing in prevalence in the very near future.

For further information around this response, please contact:

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2 Introduction

Parkinson's Tasmania (PT) considers responding to the Tasmanian Government's 20-Year Preventative Health Discussion Paper as a critical action. This is because numerous known risk factors exist in Tasmania already, and if not addressed, will materially impact the State economically, socially and culturally, well within the timeframe of this Preventative Health Strategy.

The time to act is now.

Along with the international and national Parkinson's leaders who have contributed to this submission, PT recognises the importance of prevention in addressing the growing burden of chronic diseases, including Parkinson's, and are encouraged that the government is prioritising this focus.

Parkinson's occurs in three stages: Primary (before), Secondary (during prodrome, or early signs or symptoms) and Tertiary (manifest Parkinson's).

Contributors to this paper believe that early intervention, better access to healthcare, and community-based support systems can significantly improve health outcomes for people living with Parkinson's through all three stages and can help to prevent progression. PT would like to note that contributors have been generous with their time, their knowledge, expertise and guidance and this submission is a great example of industry and sector collaboration "coming to life" in Tasmania. A list of contributors and a formal acknowledgement of their investment, appears on page 33 of this submission. Many of the contributors have lived experience with Parkinson's, are living with Parkinson's, or have been a carer of someone with Parkinson's.

Parkinson's, whilst currently managed through treatment rather than prevention, can benefit from lifestyle interventions and strategies that focus on early detection, improved quality of life, and supporting those at risk. Prevention is not just about avoiding disease but about creating an environment where Tasmanians can live healthier, longer lives through the stages of Parkinson's e.g. moving to the Secondary stage or slowing progression to the Tertiary stage. It is also about delaying the onset of clinical signs and self-management of their own care away from acute and in-patient settings.

Parkinson's Tasmania looks forward to collaborating with the Tasmanian Government to enhance awareness and develop policies that support preventative health for all, particularly those affected by Parkinson's, their families, and the broader Tasmanian community.

3 Background

Parkinson's is a chronic, progressive, degenerative neurological condition with no cure or treatments that stop disease progression. Globally, disability and death due to Parkinson's are increasing faster than for any other neurological disorder (1). Whilst the average age of diagnosis is 60-65, a significant proportion are under this age and will face different issues such as work, raising a family or caring for elderly parents. Parkinson's Tasmania is aware that in the primary and second phases of Parkinson's, people living with the condition want to be empowered to manage their symptoms and lead an independent life as much as possible.



People diagnosed with Parkinson's can have a complex range of movement related symptoms including tremor, muscle rigidity, mobility issues, with a tendency of falls and fractures. There are also non-movement symptoms such as depression, anxiety, behavioural disturbances, cognitive impairment, sleep disorders, communication and swallowing difficulties, hallucinations, dementia, sensory deficits such as loss of smell and impaired speech:



Source: Parkinson's NSW

It is a condition that is extremely challenging to manage due to its chronic and progressive nature, complicated and diverse physical and cognitive symptoms, and the fact that no single instance of Parkinson's is the same as another. There are markers of prevalence, but without no absolute cause, there can be no cure. Gene variants of Parkinson's are causative in approximately 20% of cases (21). The findings of studies such as this, means that it is likely 80% of cases can be prevented or delayed. This is a significant implication in the context of the Tasmanian Government's 20-Year Preventative Health Strategy.

The impact of Parkinson's on families and caregivers is significant as is the cost to health care systems and communities. It is for these, and many other reasons, that PT is coordinating this response to the Tasmanian Government's 20-Year Health Strategy Discussion Paper, drawing on the perspectives and views of key stakeholders, including world leading researchers and academics, special interest groups, caregivers and people living with Parkinson's.

With these contributions, this submission aims to position Parkinson's as a critical consideration when developing the Tasmanian Government's 20-Year Preventative Health Strategy.

An urgent public health response is necessary to meet the health and social requirements of people with Parkinson's and to improve functioning, quality of life and prevent disability as global longevity increases. (World Health Organisation, Technical Brief, 2022).

4 Methodology

Collecting data to respond to the Tasmanian Government's Discussion Paper on the development of its 20-Year Preventative Health Strategy involved a multifaceted approach:

- Surveys were conducted to gather a diverse range of perspectives on health priorities, challenges, and strategies for prevention. This provided quantitative and qualitative data.
- Interviews were carried out with key stakeholders, including health professionals, policy makers, and individuals with lived experiences. These interviews offered insights into the complexities of preventative health, as well as specific needs and challenges.
- The University of Tasmania's two key medical institutes (*Menzies Institute for Medical Research* and *Wicking Dementia Institute*) and MOOC also contributed valuable information on the risk factors, and potential preventative measures for neurodegenerative conditions. This provides evidence-based insights on Parkinson's and related health conditions, plus perspectives from people with Parkinson's as featured in the MOOC.
- Relevant reports and papers from leading academics and health experts from across the world were reviewed to ensure that the response to the Discussion Paper was grounded in the latest scientific research and best practices.

5 An Overview of Parkinson's

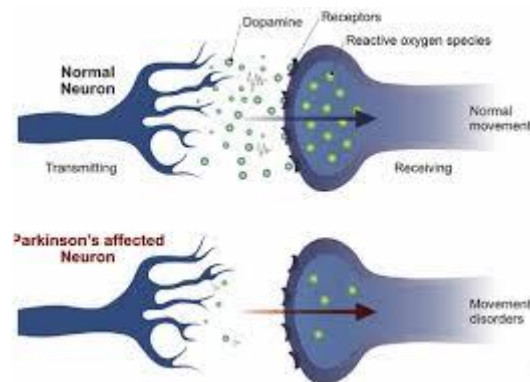
Some key facts relating to Parkinson's (5):

Fact 1: The presence or absence of risk factors **differs** between individuals. This can depend on where a person lives, their lifestyle, and their family history. Risk factors also interact with each other, making it more difficult to find out which has the strongest impact.

Fact 2: We know that the **strongest** factor for increasing the risk of Parkinson's is **ageing**. Most Parkinson's diagnoses are made in those over the age of 60, although young onset Parkinson's is also prevalent, with 1 in 10 people diagnosed being younger than 45 years old.

Fact 3: While the environment (toxin exposure, air and water pollution and modern industrial chemicals) and genes can interact with one another, approximately **10-20%** of Parkinson's cases are linked to genetic changes.

Fact 4: The neurons in our brain not only **make dopamine**, but they also **release** it into the brain and are crucial for the brain understanding and interpreting signals and information. When dopaminergic neurons die or stop producing enough dopamine, medications then act to either **increase** dopamine levels in the brain; can **act in the place of** dopamine; or **slow down** how quickly the brain uses dopamine.



Fact 5: Parkinson's often begins **20–30 years before diagnosis**, with early non-motor symptoms such as sleep disruption or loss of smell.

Fact 6: **Underdiagnosis is common**, particularly in the early stages or in rural and low-resource settings. **General Practitioners, neurologists, and geriatricians** are typically involved in diagnosis.

Fact 7: Exercising for at **least 2.5 hours a week** is important for our overall health, particularly those people who are at risk of Parkinson's, or living with Parkinson's.

Fact 8: Exercise **increases the release of** dopamine in the brain. Research shows that exercise may slow the progression of Parkinson's symptoms, but this needs to be at least "moderate intensity" (which means you are sweating or slightly short of breath).

Fact 9: A **biopsychosocial model of care** is essential, addressing both physical and emotional wellbeing, looking after both the mind and the body.

Fact 10: More specifically, there is efficiency and greater positive impact for the person living with Parkinson's and the health-care system in **establishing multi-disciplinary care teams** to support people who are diagnosed or living with Parkinson's. This includes GPs, neurologists, physiotherapists, speech pathologists, occupational therapists, psychologists, and dietitians.

6 Why is Parkinson's So Relevant to Tasmania's 20-Year Preventative Health Strategy?

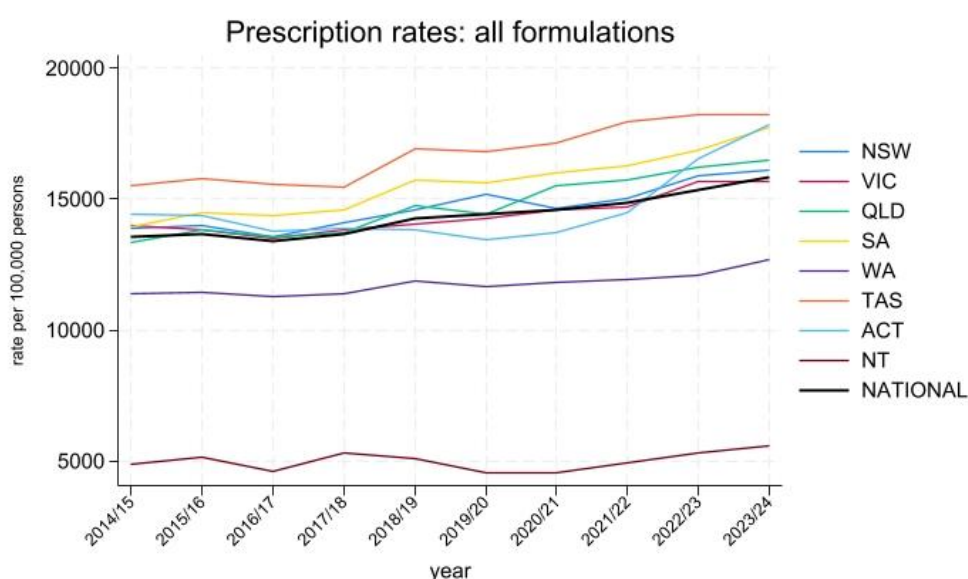
Parkinson's is of relevance in Tasmania due to our ageing population and higher-than-average rates of several risk factors as noted below:

Prevalence: There is a significant lack of consensus on the exact prevalence of Parkinson's in Australia, although it is estimated that around 220,000 people currently live with Parkinson's. Variability in data arises from differences in study methodologies, demographic factors, geographic distribution, the existence of medical teams in regional and remote communities that are trained to be aware of and understand the signs and symptoms of Parkinson's, and other general challenges in diagnosis. However, Tasmania's world-class expertise in neuro-degenerative conditions through the *Menzies Institute for Medical Research Excellence* and the *Wicking Dementia Institute*, is progressing prevalence and related studies.

The Island Clinic sleep study (3) is finding that people are at risk of Parkinson's years before they develop secondary symptoms. The study is enabling early identification of one of the risk factors for dementia, and Parkinson's, which can help to shape preventative health activity.

Associate Professor Barbara de Graaff, from the University of Tasmania, is undertaking a project to estimate the prevalence and health economic impacts of Parkinson's in Tasmania as well as nationally, using the AIHW's National Health Data Hub (NHDH). This data collection includes de-identified health and administrative data relating to all public hospital admissions, emergency department presentations, Medicare and PBS-subsidised services, the National Disability Insurance Scheme and Aged Care datasets and is presented in the following table:

Table: Prescription rates for Parkinson's medication per 100,000 population, 2014/15-2023-24

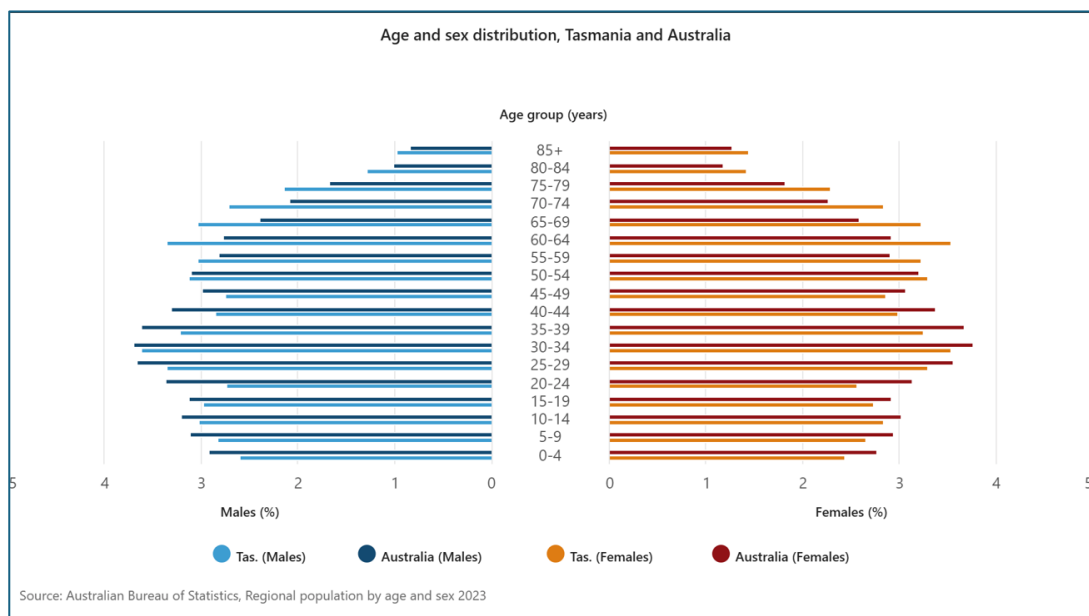


The data is clear – Tasmania has the highest rate of Parkinson's medication prescriptions nationally (largely levodopa), inferring the highest level of prevalence in the country. This is unsurprising in the Tasmanian context given the following (5):

- Parkinson's is the **fastest-growing neurological condition in the world**.
- Tasmania's population is **aging fast**, and **age is a material risk factor** for Parkinson's.
- Between **8.5 and 10 million people** are currently living with Parkinson's globally.
- The number of people with Parkinson's has **doubled over the past 25 years**.
- Parkinson's is increasing at approximately **15% per year** worldwide.
- It now affects **1 in 6 people** over the age of 65, up from 1 in 9 in earlier estimates.
- Parkinson's is **growing faster than Alzheimer's disease**.
- Higher rates than other neuro degenerative conditions, including Multiple Sclerosis (MS) and Motor Neurone Disease (MND)

The World Health Organisation has estimated that neurodegenerative diseases including Parkinson's and Alzheimer's disease will become the second leading cause of death worldwide by 2040, surpassing cancer related deaths (1). Population aging is the primary contributor to the growth in cases of Parkinson's (2) and as already described is particularly relevant in the Tasmanian context. The variability of symptoms and factors means that Parkinson's is an extremely complex disease in clinical medicine because it has a very large number of motor and non-motor symptoms (17).

Tasmanian Demographics: ABS data in the following table shows that Tasmania has a higher proportion of people over the age of 50 compared to the national average. With Parkinson's, and other neurological degenerative conditions being directly linked to age, this is a major concern from an economic, social and cultural perspective.



[Regional population by age and sex, 2023 | Australian Bureau of Statistics](#)

People are Living Longer: Today, Australians are living longer than ever before, with children born in 2023 expected to live into their 80s. Just over one-tenth of their lives will be spent with ill health, and the burden of chronic conditions remains high. Around 6 in 10 Australians are estimated to live with a long-term health condition (6) the onset of which increases with age.

Impact on Carers and Communities: The World Health Organisation notes the inequality in the availability of resources and services to provide treatment and care especially in low and middle-income countries (1). With almost two-thirds of Tasmania's population (309,000) living outside of Greater Hobart (5), and the Tasmanian Government looking to address the fact that “*Tasmanians living in rural and remote regions experience disadvantage in terms of access to healthcare and poorer health outcomes*” through its Access2Health project there is clearly a burden of care on families and communities. It is more difficult to access specialised care in rural and remote communities; and given the lack of Parkinson’s awareness and training is exacerbated in remote areas symptoms are not identified, and diagnosis can be delayed. In addition, in most Parkinson’s cases, the carer is of a similar age which leads to carer burden and possible consequential health impacts.

Economic Impact: There is clearly an impending direct and indirect economic impact on Tasmania as a direct result of increasing prevalence of Parkinson’s, let alone the direct cost of Parkinson’s on the individual, their carer and their family.

In a recent estimate (21), the average direct cost of Parkinson’s was \$9924 USD (SD, \$22,140 USD)/person/year. While more than 50% of increased Parkinson’s-related expenditure was estimated to be incurred by those in the most advanced stages, disease modification would lead to reduction in the likelihood of reaching the advanced stage, and even early-stage Parkinson’s has associated costs, related to not just to motor but also nonmotor features such as loss of employment or reduced work hours. On an individual level, Parkinson’s is life-changing, and on a societal level, it represents a significant impact on the economy (concerning given Tasmania is an economy that is already predicted to be under significant pressure).

Based on the above study and broad estimates and currency conversions, if assuming the following:

- 220,000 Australians are living with Parkinson’s
- 5% (11,000) of those are in Tasmania
- \$9924 USD is approximately \$15,000 AUD per person/year to manage their condition (noting that this figure does not consider the loss of earnings for the person living with Parkinson’s or their carer).

The above assumptions result in **\$165 million per year being a possible direct cost of people living with Parkinson’s in Tasmania each year, much of that falling to the public health system.** It is worth noting that other studies have indicated that ~\$80,000 per year, per person is the healthcare and societal cost of people with Parkinson’s in Australia. And, overall, 60–70% of Parkinson’s-related healthcare costs occur in the later stages of the condition (7). This is concerning given Tasmanian demographics. Early detection and coordinated intervention offer a strong return on investment both in quality of life and system savings.

The ParkinsonNET research program, due to be completed in 2030, will be progressing economic evaluations as part of the design and implementation of the model of care, considering direct and indirect costs and subsidisation of health services through Medicare, private health insurance, Aged Care Package or NDIS. Total annual costs incurred by the health system and people living with Parkinson’s will be reported and provide greater economic cost accuracy for the Tasmanian context.

7 Reflections on the Discussion Paper

This section provides direct commentary against the Discussion Paper, as it is assumed that much of the content in the paper will inform the 20-Year Preventative Health Strategy.

It is extremely encouraging that the Tasmanian Government is focusing on preventative health. This is because prevention via addressing risk factors and leading a healthy life after diagnosis is, at this stage, one of the best ways to combat Parkinson's. There are some parts of the Discussion Paper that needs to be addressed to ensure it appropriately accounts for Parkinson's, and the significant impact it will have on Tasmania's health system and the economy:

Page	Discussion Paper Reference or Topic	Commentary
12	Understanding the Determinants of Health – Environmental	We feel that the Environmental list should contain reference to chemical use in industries (its impact on air, water, soils).
12	Understanding the Determinants of Health – Structural	We feel that the Structural list should include capability and capacity of the health system (not just reference to whether its accessible or not).
14	The Discussion Paper notes that actions will be taken to consider several factors, including those that are targeted to greatest need and supported by national and international evidence.	This submission includes the perspectives and direct input of international experts. Indications are that the highest prevalence of Parkinson's is in Tasmania, compared to other states and territories
19	<i>"...we will work to...reduce and eliminate exposure to harmful products and behaviours."</i>	We are very pleased to read this statement, given research indicators are the onset of Parkinson's is influenced using some chemicals and pesticides in the agricultural sector and that limited genetic factors as commonly misunderstood/mistaken.
22	<i>"Protect Tasmanians from foodborne diseases through Australia's foodborne illness reduction strategy... and relevant legislation."</i>	As above.
26	Section: Improve our environments for health and wellbeing	We are pleased that this section is included in the Discussion Paper, given the use of paraquat is a key point being raised in this submission.
27	Section notes essential to ensuring good health are <i>"protection from environmental toxins such as radiation, chemicals...."</i>	As above.
28	Section notes <i>"We will...strengthen environmental health oversight through increasing the capacity of our environmental health sector to</i>	As above.

	<i>proactively regulate and inform safety standards.”</i>	
32	Healthy Ageing references	We are supportive of this being a focus in the strategy, given Tasmania’s demographics. Ageing is one of the key drivers of the progression of Parkinson’s.
35	Section: Screening	Screening is aligned to the actions that members of the Parkinson’s cohort in Tasmania will be focusing on in future grant submissions. Early diagnosis, training and support of GP’s to accurately diagnose Parkinson’s are also initiatives in the PT strategic plan. Through the University of Tasmania, and led by Professor Jane Alty, a method of screening has been developed in Tasmania – the “TASTest”. This is a brief computerised tool that is gaining global attention from other researchers and the Global Parkinson’s Genetics Program (GP2).
37- 42	Section: Take a Health Equity Approach	We are supportive of this as a focus but commentary in this section needs to include ‘aged’ or ‘older people’ given the accuracy of this sentence on page 37: <i>“there are a number of different groups within Tasmania who experience a disproportionate burden of disease.”</i> This statement is tantamount to older people, the cohort most affected by Parkinson’s. In addition, there needs to be consideration of other vulnerable cohorts, including Aboriginal or Torres Strait Island cohorts.
45	Enablers	Parkinson’s Tasmania is an enabler in the context of developing a whole-of-government, whole-of-community approach. Parkinson’s Tasmania is the ‘leading voice’ of Parkinson’s in the State. The nature of the collaborative relationships that exist between key stakeholders in the Parkinson’s cohort means a strong foundation for positive outcomes for people at risk of Parkinson’s, people living with Parkinson’s, their carers, families and communities. PT is supportive of a preventative health strategy that creates proactive effort to address one of, if not the most significant neurological conditions for Tasmania that includes the perspectives of private sector, industry, health and wellbeing champions and the research community.

The Tasmanian Government's desire to ensure cross-system efficiency, mentioned several times throughout the Discussion Paper, is very pleasing given this factor underpins the way the Parkinson's cohort operates. For example:

- The Board of PT includes international leading researchers in the areas of Parkinson's, who represent Menzies Institute for Research Excellence and Wicking Dementia Institute.
- The Incoming Chair of the Board of PT is a Director of the National Parkinson's Alliance (NPA) and a member of the Advisory Group for the NPA. The Alliance has been established by influential stakeholders across Australia to create a National Parkinson's Action Plan. This work, with almost \$1million in funding from the Federal Government, is being undertaken in 2025-26 and Parkinson's Tasmania has a key role to play.
- Dr Harley Stanton (retired WHO scientist) established the NPA and the founding Chair, is from Tasmania, leads 'Wings for Parkinson's' (a special interest and advocacy group) and has strong connections throughout the Parkinson's cohort in the State. Dr Stanton is currently living with Parkinson's (diagnosed 4 years ago).
- Members of the Board of PT are members of the Wings for Parkinson's (W4P) special interest and advisory group. W4P incorporates 30 members representing key areas around specialist care, research and advocacy from across the State. Led by Dr Stanton, Wings for Parkinson's was instrumental in establishing the National Parkinson's Alliance.
- Professor Jane Alty is a neurology clinician, researcher and educator with world-leading impact, bringing international expertise from the UK and led the Parkinson's UK clinical care audit in teaching hospital that serviced a population of about 1 million people. Professor Alty won Parkinsons Excellence awards for quality improvement projects in Leeds. After moving to Tasmania, Professor Alty joined the Board of PT and is the founder of the Tasmanian Parkinson's Project which is aiming to improve the lives of people with Parkinson's, underpinned by a national registry of people with Parkinson's, as well as other Tasmanians interested in being involved in the research ([Tasmania Parkinson's Project | UTAS](#)).
- Professor Michele Callisaya is a Principal Research Fellow at the Menzies Institute for Medical Research. Michele is an international research leader in the field of gait, frailty, falls, rehabilitation and dementia. She has successfully obtained over \$33 million dollars in research funding, most recently being awarded \$2.88 million for ParkinsonNet - an internationally recognised best practice multidisciplinary model of care. ParkinsonsNET has been shown to improve access to high-quality care and improve health outcomes by, for example, lowering disability, rates of hospitalisation and healthcare costs.
- Associate Professor Barbara de Graaff is a leading public health researcher at the Menzies Institute for Medical Research, University of Tasmania. Her work focuses on generating health economic and epidemiological evidence to inform policy and practice for chronic diseases. With over 80 publications and \$10million in funding, Associate Professor Barbara de Graaff brings extensive expertise in leading multidisciplinary research teams.
- PT has a diverse and skilled Board that also includes Michelle Mortensen (Occupational Therapist), one of only two certificated and practising LSVT BIG (Individualised Physical Treatment) clinicians in Tasmania.

8 Response to the Discussion Paper

8.1 Challenges for People Living With Parkinson's (Primary, Secondary & Tertiary Levels of Onset) – Prevention Through the Stages

As a progressive neurological disorder, Parkinson's primarily affects movement, leading to tremors, stiffness, slowness, and balance issues. However, the impact reaches into nearly every aspect of a person's life. Individuals often struggle with tasks that were once routine, such as buttoning a shirt, writing, or simply walking across a room. Beyond the physical, Parkinson's can bring cognitive decline, emotional and cognitive hurdles, including depression, anxiety, and memory problems. These invisible non-motor symptoms often go unnoticed but can be just as debilitating as motor difficulties, such as tremoring. The unpredictable progression of the disease also adds a layer of complexity and uncertainty.

The following is a list of specific challenges for people living with Parkinson's. Given the condition moves through the primary, secondary, and tertiary stage. Furthermore, there is the possibility to delay or 'prevent' progression of the condition through these phases, this list is relevant context:

- **Mental health** issues such as depression and anxiety are common.
- **Daily life challenges** (mobility, cognitive impairment, employment, social participation).
- **Employment impacts**, for those people living with Parkinson's and are of working age have little peer support - although peer support exists for older people via Parkinson's Tasmania (delivered by volunteers).
- **Social isolation** leading to reduced social engagement, increases the risk of depression and loneliness and the need for psychological and social supports being available.
- **Young onset or early onset** :changing the narrative around those impacted by Parkinson's, as it is currently understood as an old man shaking disease.
- **Stigma** more broadly, particularly around the abilities of people living with Parkinson's.
- **Incontinence** is an issue for many people living with Parkinson's.
- **Medication** needs to be on-time throughout the day and night. Unless someone has a dual dopa pump (which provides a constant flow of dopamine and currently only available in Launceston) then the person living with Parkinson's needs to manage their medications orally.
- **Access** to the right allied health care trained in Parkinson's, in recognising symptoms, diagnosis and treatment.
- **Financial challenges**, given the progressive nature of Parkinson's affecting a person's ability to work, leading to financial strain and further potential loss of social connections associated with employment.
- **Care giver burden** – family members and caregivers often face significant physical, emotional and financial challenges in supporting loved ones with Parkinson's.
- **Lack of comprehensive care plans** that take a multi-disciplinary approach to a person's needs, even as they enter the primary stage of the condition.

- **Significant delay** from diagnosis to see specialist (particularly neurological or movement disorder specialist).
- **Education is lacking** at the time of diagnoses in Tasmania, compared to other states. This is largely caused by the limited level of expertise that exists in the health system as it relates to Parkinson's. Awareness, knowledge and education is critical to help those people diagnosed to access support, particularly during the early stages of the condition.
- **Progression** to Parkinson's related dementia is a challenge. Dementia is monitored and managed through the University of Tasmania's Island Clinic, a bulk billed clinic that is operated by the Wicking Institute for Dementia Research (UTAS). There is no support provided to Wicking by the Government to deliver these services. There are possibilities for parallel services to be provided to people at risk of Parkinson's or living with Parkinson's.
- **Deep Brain Stimulation** treatment is only available in Melbourne and therefore, has a greater financial cost (impact on poorer people and/or in rural areas). Deep Brain Stimulation has been proven to assist people with Parkinson's. Referral processes are lagging, and some people are not able to access this treatment at all due to travel and health care costs.

8.2 Gaps in the Healthcare System in Tasmania Relating to Prevention

The Tasmanian Healthcare System could improve significantly in the following areas to help reduce the impact of Parkinson's:

1. Access to Specialised Care for Diagnosis and Treatment

The World Health Organisation (1) recommends that diagnosis is undertaken in primary care facilities by properly trained health-care workers, including general practitioners and specialist nurses. Complex cases in regional and remote communities should be triaged to secondary care for further, specialised assessment - for example, by neurologists, when available.

Access to specialised care in the Tasmanian Health System is critical as it is a prevention strategy for progression through the primary, secondary and tertiary stage of the condition where symptoms worsen and health care system costs and burden increases.

Access to specialised Parkinson's care i.e. easy access to neurologists or movement disorder specialists are also important to appropriate diagnosis, treatment and management. This is particularly lacking in most of Tasmania which is problematic in rural areas.

The role of digital tools in medical systems is therefore important, although not widely used in Tasmania yet. Telemedicine, including sharing of videotaped neurological examinations, can assist with diagnosis and support. The use of digital tools and of telemedicine is aligned the WHO Global strategy on digital health 2020–2025. Interventions for rehabilitation, including physiotherapy, occupational, speech and language therapy, diet management and psychological interventions can, and should, be delivered in this way particularly when geographical challenges exist (1).

The significance of early, compassionate intervention at the time of diagnosis shouldn't be underestimated. Delivering a diagnosis of Parkinson's should be approached with empathy and hope, requiring healthcare providers to be well-informed and educated, particularly given the myriads of psychological, systemic, physiological and personal challenges and considerations for someone with Parkinson's as noted in the diagram below. Health professionals who are educated in the areas of Parkinson's support can help to mitigate the psychological impact of diagnosis, provide immediate information, and begin the process of long-term management planning (9).

Diagram – Important Considerations for getting the diagnosis of PD



Fig. 1. Important considerations for getting the diagnosis of PD (NMS-non-motor symptoms).

2. Parkinson's Education for GP's, Nurses, Allied Health professionals and Neurologists AND funding the employment and training of Specialist Parkinson's Nurses

Specialist nurses play a vital role in supporting people with Parkinson's and helping to prevent its progression. According to the UK National Institute for Health and Care Excellence (NICE) Guideline for Parkinson's, all individuals living with the condition should have regular access to a Parkinson's Nurse Specialist. These professionals are essential in ensuring consistent clinical monitoring, medication adjustments, and providing a continuous point of contact for support, including home visits when necessary. They also serve as a trusted and knowledgeable source of advice on both medical and social concerns, helping to improve the overall quality of life for patients (16).

3. Multi-Disciplinary Care Coordination

Parkinson's requires input from a range of healthcare professionals including Neurologists, Physiotherapists, Occupational Therapists, exercise physiologists, speech therapists, mental health specialists, social workers, dieticians and continence nurses. However, there is a lack of coordinated care between these professionals leading to fragmented treatment and delays in addressing the full spectrum of symptoms, let alone a lack of health professionals with expertise in treating people living with Parkinson's.

A multi-disciplinary approach is essential in supporting individuals with Parkinson's disease due to the complex, progressive, and highly individualised nature of the condition. Treatment and care must go beyond a standardised approach (18). Clinicians must engage in shared decision-making with patients, integrating their personal goals, values, and life contexts. This patient-centred philosophy acknowledges that "one size cannot fit all," both in diagnosis and ongoing management,

a concept that is being progressed via the ParkinsonNET research program through the Menzies Institute for Research.

Since Parkinson's affects motor and non-motor systems and manifests differently in each person, a rigid or uniform treatment plan would fail to address the unique challenges faced by individuals.

The need for a collaborative and multi-disciplinary approach to care and a team-based approach has reached international consensus (18), with a model that includes neurologists, physiotherapists, occupational therapists, speech-language pathologists, mental health professionals, and social workers, among others. The model ensures comprehensive support for the wide range of symptoms Parkinson's patients may experience, from mobility issues to communication difficulties and psychological distress. The consensus statement also stresses the importance of coordinated care throughout all stages of the disease to maintain function, independence, and quality of life.

Essential health services in an interdisciplinary approach to care can improve functioning and the quality of life of people with PD and reduce the strain on carers (World Health Organisations, Technical Brief, 2022)

The health system gaps in Tasmania that have been discussed highlight the need for a more integrated, accessible and comprehensive healthcare system for individuals diagnosed, and living, with Parkinson's. We are in a unique position in Tasmania, with the work being undertaken and research and medical expertise that exists to develop solutions. The priority preventative health actions or initiatives are described in section 8.8 of this submission.

8.3 Barriers to Accessing Healthcare and Preventative Health Services relevant to Parkinson's

There are numerous barriers to accessing the right healthcare, at the right time and in the right environment. These barriers include:

- **Lack of public awareness**, particularly about the signs and symptoms to be aware of that may be evident in the primary stage of the condition, a key stage for prevention.
- **No support post diagnosis** therefore many people go for over 12 months or when a crisis occurs before seeking any support to access any funding body (drawn from direct and personal anecdotes and experiences of some collaborators).
- **Geographic challenges** (rural and regional access). This is a key driver for the ParkinsonNET research project, led by Professor Michele Callisaya.
- **Financial constraints** (cost of services, treatment, or medication).
- **Poor general health literacy** across the community.
- **Lack of knowledge of health professionals** on diagnosing Parkinson's and then the best approach to care for the patient.
- **Lack of guidelines in Australia for Screening, Diagnosis and Best Practice Care.**
- **Limited specialist access** (e.g. Parkinson's nurses, neurologists, and allied health professionals).
- **Lack of coordination of My Aged Care, NDIS, and the State Health System.**
 - Complexity of the My Aged Care system. Challenges include complicated processes, long wait times, inadequate communication between health and aged care services. These issues contribute to inadequate care quality and accessibility particularly for older people living with Parkinson's. In addition, Level 1 and Level 2 aged care packages don't have sufficient funding to provide supports in the Primary or Secondary stage of Parkinson's prevention. Many Aged Care Assessors do not consider, therefore do not recommend, the short-term restorative care program to allow quick and intensive access to allied health.
 - For those patients under 65 years old may not meet or perceive they don't meet the criteria for NDIS. Better education is needed for GPs to understand both the NDIS assessment process as well as the patient. Parkinson's may result in permanent impairment that affects daily functioning, but this does not just refer to mobility.

Some of these challenges require systematic reforms, that include simplifying access processes, investing in workforce training and ensuring the right care at the right time to improve the accessibility and quality of services.

8.4 Programs That Are Working Well in Tasmania

The following services work well **but require expansion statewide**, with specific investment in regional and remote communities where populations are becoming older. Specialists are difficult to access and cost prohibitive in regional and remote communities. The 20-Year Preventative Health Strategy should consider ways to build and scale these services across the State:

- Support groups (e.g. Parkinson's Tasmania)
- Neurology Nurse Program (needs expansion in quantity and regional location)
- Exercise physiologists
- Physiotherapy
- Speech therapy
- Occupational therapy
- Social and recreational programs (e.g. Dance for Parkinson's)
- Tasmanian Parkinson's Project
- The Parkinson's MOOC
- The short-term restorative care program for over 65's
- Mental health support alignment
- Newly diagnosed clinics
- Peer support (especially for early onset and young onset)

8.5 Priority Preventative Health Areas for Tasmania

The following critical actions are recommended to help prevent Parkinson's through addressing several key risk factors for Tasmania:

- 1. Environmental:** It is believed that up to 80% of Parkinson's may have environmental triggers, hence focus on reducing the environmental toxins in air, land, and water must receive high priority in the Tasmanian Government's 20 Year Preventative Health Strategy. Factors such as exposure to environmental toxins and specific blows to the head, all of which can be reduced with prevention efforts, may account for nearly 1 in 3 cases of Parkinson's among men, and 1 in 4 among women according to a study of the neurodegenerative disease by researchers at the University of Alabama at Birmingham (UAB), who have noted that "*intrinsic risk factors (age, sex, and genetics) are inescapable, but environmental factors are not.*" (20)

The World Health Organisation have already called to ban pesticides (e.g. paraquat and chlorpyrifos) and chemicals (e.g. trichloroethylene) which have been linked to Parkinson's and develop safer alternatives (1). The use of paraquat has already been banned for use in several major countries, such as the USA and China.

Paraquat is a toxic herbicide used for weeding and pest control. Whilst alternatives would need to be found for important Tasmanian industries such as forestry, general agriculture and poppy farming, it is an internationally acknowledged risk-factor in the onset of Parkinson's. Coupled with the demographics in Tasmania, alternatives must be implemented to reduce the risk that paraquat presents to humans (9). There is currently a national review being undertaken around the use of paraquat in particular: <https://www.apvma.gov.au/news-and-publications/news/review-timeframes-paraquat-and-diquat-extended> and the ABC has covered [paraquat and Parkinson's](#).

- 2. Screening & Early Detection:** Screening and early detection are critical to identifying Parkinson's in its initial stages, often before symptoms appear, and preventing progression to secondary and tertiary stage. Being proactive significantly increases the chances of successful interventions and can reduce the severity of the condition. Early intervention can prevent progression, lower treatment costs, and improve long-term outcomes and quality of life. Early detection helps in reducing the burden on the Tasmanian Healthcare system by avoiding emergency interventions and complex treatments. Through routine screenings, healthcare providers can monitor at-risk populations, promote healthier lifestyles, and empower patients with the knowledge needed to make informed decisions about their health.

Led by Professor Jane Alty, Wicking has developed the "TAS Test" - a brief computerised tool that is gaining global attention from other researchers and the Global Parkinsons Genetics Program. TAS Test is a world-first study to develop an online test that measures people's hand movements, speech patterns and cognitive abilities through their home computer. The low-cost screening test will help to predict who is at higher risk of neurological conditions, including Parkinson's. TAS Test is based on a new computer test that uses Artificial Intelligence (AI)-based "computer vision" to precisely measure hand movements (10,11,12,13,14).

There is a need for Government policy to be established in relation to the early screening initiatives and then applying funding to 'roll out' these approaches to the population. International philanthropists are already interested in this work.

3. Ensure Specialist Skills in a Proactive rather than Reactive Support Approach

Anecdotal information from the Tasmanian Health Service indicates that the number of people who are admitted to Parkinson's is **three times higher** than those that don't have Parkinson's. Nurses who are specialists in supporting people who are progressing with Parkinson's and more specifically, a multi-disciplinary team will keep people out of hospital. Specialised care helps prevent admissions, which has an estimated cost of around \$2,000, per day according to the Australian Institute of Health and Welfare. This cost **does not** include specialist care. If just one hospital admission can be prevented based on an average stay in hospital, it will realise significant benefits to the health budget.

In addition, a proactive rather than reactive approach should be embedded in any healthcare setting e.g. regular, scheduled assessments, not just after someone has a fall.

Tasmania is also lacking in the number of neurologists with only 17 neurologists registered in the State (December 2024) compared to South Australia with 57 neurologists (the State closest to Tasmania's demographic profile) (www.medicalboard.gov.au/news/statistics.aspx).

More broadly education is lacking in relation to Parkinson's in the acute care setting in Tasmania, compared to other states. Awareness, knowledge and education is critical to help those people diagnosed to access support, particularly during the early stages of the condition.

4. Supporting Physical Activity and Social Engagement

Exercise plays a vital role in the prevention and management of Parkinson's. Research highlights the significant benefits of various physical activities, particularly aerobic exercise, tai chi, qi gong, and yoga, in improving both motor and non-motor symptoms of the condition. These forms of exercise positively impacts motor function, depression, and overall quality of life. Notably, aerobic exercise enhances cardiovascular health and neuroplasticity, potentially slowing the progression of neurodegeneration in Parkinson's (19). Exercise also naturally releases dopamine.

8.6 The Tasmanian Government's Role

The Tasmanian Government plays a crucial role in promoting preventative health by creating policies, programs and systems that encourage healthy behaviours and reduce the risk of Parkinson's. This includes the following initiatives:

- Ensuring a consolidated and impactful effort exists in all of the activities currently happening in Australia and the world, that will directly impact Tasmania and Tasmanians.
- Coordinating a statewide Parkinson's prevention and early intervention plan. Plans for this should be supplementary to the creation of the Tasmanian Government's 20-Year Preventative Health Strategy and developed in partnership with key enablers in the system.
- Providing seed funding to Parkinson's Tasmania (PT), as the voice of Parkinson's in the State, and enable PT to provide education, advocacy and engagement to and on behalf of the Parkinson's community.
- Facilitating the implementation of the new National Parkinson's Action Plan (Parkinson's Tasmania is the lead connector in this Federal Government funded initiative).
- Funding or leading public awareness and health literacy campaigns. These campaigns help people make informed choices to prevent chronic conditions.
- Funding and access to preventative care such as screening for early detection and ensure services are accessible to everyone particularly the vulnerable or under-served populations.
- Expanding access to Parkinson's nurses, specialists, allied health and exercise programs, for example exercise programs and neurological physiotherapists, occupational therapists and speech pathologists in all parts of Tasmania. The North-East and North-West of the State are a good example of areas that have no relevant services.
- Increasing funding for Parkinson's research and public health innovation.
- Providing more community-based support and rehabilitation programs, particularly in relation and remote areas of Tasmania.
- Supporting collaboration between healthcare providers, researchers, and advocacy groups.
- Policy development and regulation (setting standards for public health), an area that is significantly lacking per initial assessment of the landscape by the National Parkinson's Alliance.

8.7 Broader Community Support for People with Parkinson's

Increasing awareness of Parkinson's in the general community as well as the risk factors around the onset of Parkinson's, is important for prevention and reducing shame and stereotype. This includes:

- Engaging with public campaigns focusing on the importance of regular exercise to improve mobility, flexibility and overall health, including healthy eating. Programs need to be tailored for individuals, acknowledging the three stages of prevention and the progression of disability throughout the three stages (Primary, Secondary and Tertiary).
- Collaboration across the community and government sector to ensure that services are properly coordinated, effective reach and community engagement is maximised for the programs that are available.
- Education at a grassroots level, which is supported by government initiatives. Big media challenges, such as the big freeze from MND at AFL games, are needed to increase the general profile of Parkinson's in the community.
- Mental health awareness to promote accessing mental health services and participating in mindfulness or cognitive therapies to improve emotional wellbeing and raise the importance of having a healthy brain.
- Social connection initiatives, to maintain social interactions.
- Undertaking the new Parkinson's Massive Open Online Course that has been developed by the University of Tasmania. Improving education and knowledge via this course is a positive community activity in prevention.
- Joining the Tasmania Parkinson's Project run by UTAS, which will help reinforcing data relating to the risk factors for Parkinson's and provides participants with webinars and other information relation to the condition.
- Engaging with Parkinson's Tasmania, for information, support, advice and guidance as the leading voice for Parkinson's in the State.
- More literature available at grassroots e.g. GP waiting rooms, highlighting and helping health literacy around Parkinson's and services available.

8.8 Preventative Health Actions or Initiatives

The contributors to this submission to the Discussion Paper are from different parts of the Parkinson's community. These contributors have brought together research, health economist insights, personal experience, allied health, and carer experience, from both national and international perspectives, to reach the following priority actions:

Action	Outcome or Impact
1. Ban the pesticides (e.g. paraquat and chlorpyrifos) and chemicals (e.g. trichloroethylene) which have been linked to Parkinson's and develop safer alternatives as per WHO guidance and in-line with other countries such as the USA and China.	• Reduction in evidence-based risk factors that trigger the onset of Parkinson's • Reduced prevalence of Parkinson's • Improved health outcomes for Tasmanians • Improved economic outcomes for the State
2. Accelerate action to reduce levels of and exposure to air pollution, a risk factor for Parkinson's and other noncommunicable diseases, including Alzheimer's disease, respiratory disease, heart disease and stroke.	• As above
3. Introduce a digital screening program that includes simple diagnostic tools and education on their use to people over 50 years old (parallel with bowel cancer screening).	• Early identification of people that are likely to develop Parkinson's • Prevention initiatives can be put in place • Ability to prepare and plan for supports needed (personal and State) • Improved health outcomes for Tasmanians • Reduced health system impacts • Economic benefits for Tasmania
4. Focus on the creation of multidisciplinary care models within the health system to focus on providing comprehensive and patient centred care. These models involve collaboration across healthcare providers to ensure that people with Parkinson's have access to a seamless and coordinated health care experience.	• Improved health and healthcare outcomes for Tasmanians • Cost efficiencies through monitoring and prevention planning
5. Introduce Parkinson's clinics and expertise centres. These centres bring together neurologists, physiotherapists, occupational therapists, speech therapists, psychologists and	• Comprehensive and coordinated care provided for Tasmanians, delaying and

other specialists to offer holistic care. The model aims to improve diagnosis, treatment, and support for patients across the stages of progression	preventing progression especially after initial diagnosis • Help people navigate the system and ensure a multi-disciplinary approach to help them self-manage their Parkinsons their way
6. Supporting public awareness campaigns and increase knowledge about the condition and promote early diagnosis. These campaigns aim to:	• Reduce stigma, inform the public about the symptoms and available treatments • Encourage lifestyles that will prevent Parkinson's • Encourage people to seek help early to prevent progression
7. Enable and support Parkinson's Tasmania to be a sustainable organisation for people living with Parkinson's. Parkinson's Tasmania can be the coordination point and secretariat for other key stakeholder groups in the Parkinson's cohort and provide a centralised voice on policy and related matters. Navigating the complex health system is another gap that exists, and Parkinson's Tasmania could assist as a key enabler for the 20 Year Preventative Health Strategy.	• Referral to services and identification of preventative initiatives that can be put in place • Advocacy and leadership regarding prevention • Improved health and healthcare outcomes for Tasmanians
8. Work with the Federal Government to pilot GP education for enabling early diagnosis of Parkinson's and ensure the same Parkinson's specific education is provided to other allied health professionals.	• Early identification of people that are likely to develop Parkinson's • Prevention initiatives can be put in place • Ability to prepare and plan for supports needed (personal and State) • Prevention of progression • Improved health outcomes for Tasmanians • Reduced health system impacts • Economic benefits for Tasmania
9. More Allied Health professionals trained in working with people who have neurological diseases, and more of them in the regions. Ensure they are delivering care according to guidelines that is proactive from time of diagnosis.	• As above • Cost savings, key to preventing expensive admissions to hospitals

	• Reduced pressure on community services such as My Aged Care and NDIS
10. Introduce more neurologists	• Improved health outcomes for Tasmanians • Reduction in wait time after initial diagnosis (often a long wait up to a year) • Reduction in wait time between consultations (often people are only able to see a neurologist once a year due to the staff shortage)
11. Providing funding for Critical Care Nurses that are trained and skilled in Parkinson's care to help prevent progression and functional decline, referring to both pharmacological and non-pharmacological interventions as the progress of the condition moves through all three stages (primary, secondary and tertiary).	• Cost savings, key to preventing expensive admissions to hospitals.
12. Increasing the promotion of healthy behaviour to the general population (e.g. exercise and diet) along the life-course to reduce the risk for Parkinson's and to enhance potentially protective factors.	• Reduce stigma, inform the public about the symptoms and available treatments • Encourage lifestyles that will prevent Parkinson's • Encourage people to seek help early to prevent progression
13. Increasing access to community exercise programs and dieticians for people with Parkinson's, especially those with more severe disability (e.g. people who are having multiple falls may have difficulty and find it confronting to access a public gym and these facilities may be able to offer classes tailored for people living with Parkinson's).	• Encourage lifestyles that will prevent Parkinson's • Improve the health of Tasmanians
14. Investing in research initiatives to better understand Parkinson's, develop new treatments and improve patient outcomes. Collaborative research is supported by government agencies as well as private institutions and academic research centres to find new ways to slow disease progression and improve quality of life.	• Identify and develop initiatives that will prevent Parkinson's and its progression • Improved health outcomes for Tasmanians • Reduced health system impacts • Economic benefits for Tasmania

9 Conclusion

Tasmania has a unique opportunity and responsibility to lead the nation in the prevention and early intervention of Parkinson's. With the fastest-growing burden of this complex condition, and with known risk factors already present across the State, immediate and deliberate action is essential. This submission has brought together the knowledge, experience and commitment of world-leading experts, local stakeholders, and people living with Parkinson's to present a comprehensive and evidence-based roadmap for change.

As dementia prevention has become widely accepted within a decade, so too can Parkinson's prevention. Through leadership, investment, and collaboration, Tasmania can build a healthier future for all, reduce the long-term burden of Parkinson's.

We urge the Tasmanian Government to embrace the recommendations outlined, particularly those relating to environmental risk reduction, early detection, public education, and coordinated care models. Prevention is no longer aspirational - it is achievable, and essential. The strong research infrastructure, ageing population, and the State's small scale position Tasmania as the ideal environment to pilot innovative solutions that could transform Parkinson's care and prevention locally and nationally.

10 Parkinson's Tasmania Overview

Parkinsons Tasmania (PT) is a non-profit organisation focused on providing support, education, and advocacy for individuals living with Parkinson's in Tasmania. Established 40 years ago to serve the needs of people affected by Parkinson's, PT has historically played a role in raising awareness and fostering a better understanding of this progressive neurological condition and provides a network for people with Parkinson's to connect with others facing similar challenges, offering a sense of community and shared experience.

PT has a clear direction for the future, with a vision of having a Parkinson's community that is empowered to improve their wellbeing by living full and active lives. The organisation's strategic plan provides a guide for action and long-term sustainability, driving meaningful change and enhance support for individuals living with Parkinson's. These factors underpin the action of submitting a collaborative response to the Tasmanian Government's Discussion Paper regarding the development of a 20-Year Preventative Health Strategy.

A system-wide approach was critical to the development of the PT Strategic Plan 2025-2026 – 2028-2029 ensuring collaboration, innovation and care of the Tasmanian community is centre to all efforts. Multi-disciplinary care approaches, improving access to professional development and training pathways for GPS, using data to inform decisions, community led engagement and awareness initiatives, support groups, research partnerships, localised place-based activity, and collaboration are some elements that appear in PT's strategic plan and feature in the Discussion Paper's potential key actions for the 20-Year Preventative Health Strategy. This alignment is pleasing.

In its long history PT has had so far, it has been enabled by volunteers both at the Board (standard for a community sector organisation) and operational level. This has created an organisation that has connection through the community, creation with passion, dedication and personal commitment to the cause. However, the environment is changing, and additional workloads and personal circumstances have resulted in the volunteer model no longer being sustainable for PT. There are several external factors that require PT to be far more active in advocacy, policy development and community information and support. These include:

- National Parkinson's Alliance
- Increasing prevalence of Parkinsons
- Greater demand for services
- Growing government policy activity
- Prominence nationally and internationally
- Research activity in Tasmania
- Government grants offered
- Philanthropic interest and opportunity

The work in these areas cannot be delivered by volunteer effort alone. PT will need to work in partnership with the State Government to ensure that the views of Tasmanians living with Parkinson's, their families and the broader community are unified and positioned well in the national context in particular, that services are delivered to those in need, and that the impact of the increasing prevalence of Parkinson's in Tasmania doesn't have an unmanageable impact on the social, cultural, and economic prosperity of the State.

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- Wicking Dementia Institute ([Wicking Dementia Research and Education Centre | Study Now | UTAS](#))
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- Professor Jane Alty ([Jane Alty | About | University of Tasmania](#)) and Board member - Parkinson's Tasmania
- Professor Michele Callisaya ([Michele Callisaya | About | University of Tasmania](#))
- Associate Professor Barbara de Graaff ([Barbara de Graaff | About | University of Tasmania](#))
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- Linda Jomartz, Board Member – Parkinson's Tasmania (carer)
- Michelle Mortensen, Occupational Therapist and Board member - Parkinson's Tasmania
- Pauline Domeney, Board Member – Parkinson's Tasmania (facilitates all statewide support groups for Parkinson's Tasmania).

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13 Appendix 1: Parkinson's TAS Cohort

Menzies Institute for Medical Research

"Menzies" is focussed on improving health outcomes through high-quality, translational research. The Institute leads and collaborates on major studies into chronic diseases, including neurological conditions such as Parkinson's. With prominent researchers such as Professor Michele Callisaya, it is supported by national and state funding (Menzies and Wicking – co-developed the Parkinsons MOOC).

Wicking Dementia Institute

An interdisciplinary institute that combines research, education, and community engagement to improve the lives of people living with dementia. Based at the University of Tasmania, the Wicking Institute leads both national and international programs, offers free online courses and builds evidence to strengthen dementia care, with support from government and philanthropic funding (Menzies and Wicking – co-developed the Parkinsons MOOC).

University of Tasmania

A public research university that supports statewide and national health initiatives through academic leadership, research infrastructure, and clinical partnerships. It hosts institutes such as Menzies and Wicking, and plays a key role in training healthcare professionals, developing research talent, and facilitating collaborative health programs across Tasmania and beyond.

Wings for Parkinson's (W4P)

Subject-experts that raise awareness to support Parkinson's research and care initiatives in Tasmania. W4P supports local research projects, invests in education and training for healthcare professionals, and funds innovative approaches to improve quality of life for people living with Parkinson's. Led by Dr Harley Stanton, W4P was instrumental in the formation of the National Parkinson's Alliance, which helped secure subsequent funding from the Australian Government.

The Tasmanian Parkinson's Project

This collaborative research initiative seeks to better understand the causes, progression, and treatment of Parkinson's disease in Tasmania. The project collects clinical and personal data, with the goal of improving diagnosis and care.

The Island Project

A multidisciplinary research program by the University of Tasmania that investigates the causes and early markers of neurodegenerative diseases among Tasmanians. The project uses population-level data and advanced imaging to identify risk, resilience factors and aims to translate research findings into prevention and care strategies.

ParkinsonNET

A new research project based on the evidence-based Netherlands multidisciplinary model of care. The model has demonstrated improved health outcomes and lower healthcare costs by improving access to high quality care. Key components include networks of health professionals, development of training in allied health professionals and community of practice, and tailored education for people living with Parkinson's. The model is being developed and tested via funding from the Australian Government Research Grant and led jointly by Victoria and Tasmania and Professor Michele Callisaya (Research Fellow at the Menzies Institute for Medical Research).

14 Appendix 2: Personal Stories (from the MOOC)



Barbara Salsberg Mathews was diagnosed with Parkinson's at 60 in January 2020, after years of symptoms dismissed as ageing or essential tremor, a former high school art and drama teacher, now 65, has had to completely reshape her life. A visual artist and former mime artist, she is married with two adult children. It was through painting that she realised something was wrong, as she began struggling with fine detail in her hyper realistic work. The diagnosis was devastating - she felt she had to "rewrite her future." At first, she kept it hidden, leading to depression, isolation, and a retreat from both painting and social life. She says, *"When I told people I have Parkinson's, they stopped looking and listening to me... I became invisible, and all I was, was a disease."* Anger at the disease became a turning point. She returned to art, using painting and illustration to process her experience and reconnect with the world.



Lynn Elliott has a deeply personal connection to Parkinson's, with her father, husband, and now herself all diagnosed. Her father was the first, struggling with limited awareness and early detection methods. Years later, her husband was misdiagnosed, despite clear behavioural changes. He once said, *"Look at all those cockatoos,"* though there were none, highlighting the hallucinations common in Parkinson's. Lynn's own symptoms began subtly: difficulty walking and finger stiffness. Her diagnosis came unexpectedly from a lung specialist in Launceston, who recognised the signs without prior consultation. Initially, her symptoms were dismissed as grief after her husband's death, but a chance visit to a GP confirmed her suspicions. While the diagnosis brought relief after years of uncertainty, Lynn stresses that Parkinson's isn't a death sentence. *"Just be positive. Those were my thoughts with it all,"* she says, encouraging others to stay active, live well, and avoid self-pity. Though awareness has improved since her father's time, Lynn believes there's still much work to do. Her message is clear: focus on life, not limits.



Dr Harley Stanton, a former public health doctor with the WHO working on reducing tobacco use, was diagnosed with Parkinson's in 2019. His main symptoms include body stiffness, difficulty running and cycling, and tremors. His diagnosis was initiated by his GP, who noticed his facial masking, prompting a referral to a neurologist. Dr Stanton initially struggled with sharing his diagnosis, saying, *"At first, I didn't want to tell anyone. But hiding it isn't the way forward."* He stresses the importance of *"bringing Parkinson's out of the closet,"* noting that about 60% of people go silent after diagnosis, which can be discouraging. Dr Stanton rejects the stigma and stereotypes around Parkinson's. He encourages people to stay socially engaged, connect with support groups, and stay informed. He also advocates for participation in research, particularly the Parkinson's project in Tasmania. *"Take part in some of the research and testing that is now becoming available."*