Parkinson's Victoria Inc

Annual Report 2006/2007

Parkinson's
Victoria

Together we make a Difference

About Parkinson's Victoria

Parkinson's Victoria is the peak body representing the interests of people living with Parkinson's in Victoria.

We provide the following services:

- Information, advice and counselling
- Statewide network of 46 support groups
- Education
- Advocacy
- 1800 information line
- Web site
- Support research
- Parkinson's community awareness

Our Philosophy

People living with Parkinson's and their families are individuals with equal value to all other members of Australian society. They have the right to treatment and care by knowledgeable professionals, the right to appropriate support services and the right to have the best quality of life possible. We recognize and respect the individuality of those affected by Parkinson's.

Our Vision

A world without Parkinson's

Our Mission

That all people living with Parkinson's have access to comprehensive and relevant services, encouraging independence and improved quality of life. We achieve this by providing information, education, advocacy and support services to all those living with this chronic, progressive neurological condition, their families, carers and allied health professionals.

Our values

Our values underpin everything that we do. We are:

- *Sensitive to the needs of people living with Parkinson's*
- *Accountable to our stakeholders and transparent in the way we do business*
- *Innovative through valuing new ideas, knowledge, experience and research*
- *National in our outlook. We are committed to a vibrant national organization*
- *Caring for people in the delivery of our services*
- *We value integrity through acting with honesty and according to our values*

The significance of the tulip

In 1981, a renowned Dutch horticulturalist - Mr J W S Van Deer Wereld, who had been diagnosed with Parkinson's - registered his prize cultivar with distinctive red and white petals, The Dr James Parkinson's bulb. This was in honour of both the International Year of the Disabled and Dr James Parkinson's, who is credited as being the first to formally recognize and document the symptoms of the condition in *An Essay on the Shaking Palsy* (1817). Parkinson's disease was then known as paralysis agitans. The term "Parkinson's disease" was coined later by Jean-Martin Charcot. Today, the tulip has been adopted as the world-wide symbol for Parkinson's and Parkinson's organisations.

Patron:
The Governor of Victoria

Board members 2006-07

Royce Pepin:
President AM, MBE, GCSJ, Ph.C

Kate Brown:
Vice President

Peter Walker:
Chairperson Finance Committee

Sandra Eisner
Fred Van Ross
Mary Jones

Peter Venosta:
resigned September 2006

Peter Raymond:
appointed September 2006

Staff members as at 30 June 07

Glenn Mahoney:
Chief Executive Officer

Amanda Spillare:
Client Services Coordinator

Donna Willis:
Administration Officer

Victor McConvey:
Parkinson's Nurse Specialist

Judith Mooney:
Marketing Coordinator

Maz Chowdhury:
Finance Officer

Catherine Watson:
Community Development Worker

Denise Perkins:
Administrative Assistant

Anne Atkin:
Volunteer Librarian

Parkinson's Victoria Inc.

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info@parkinsons-vic.org.au

Front cover images:

(clockwise from top right):

Dr. Justin Rubio, from the Howard Florey Institute; President Royce Pepin with 2006 Sir Zelman Cowen Award recipient Merl Bridges; Members of the Ringwood Support Group; NAB staff volunteering their time with us; POP founder Nerissa Mapes with celebrity Russell Gilbert; Catherine Watson at our Carex expo display stand)

Parkinson's Fact: Every day, 25 Australians are told they have Parkinson's.

President's Report

Together we make a difference. Since the organisation's inception in 1981, the ethos of partnership has been fundamental to the success of Parkinson's Victoria.

Today, we share vital partnerships with people living with Parkinson's, families, generous volunteers who make such a wonderful contribution, support groups, dedicated staff, researchers, donors, committees and funding bodies, who all work together to reduce the impact of Parkinson's.

Our sincere thanks and appreciation to all who have contributed in their unique way to make a difference.

We acknowledge and thank Sir Zelman Cowen for permitting us to name our highest volunteer award in his honour. The inaugural ***Sir Zelman Cowen Award***, which recognizes outstanding service, was presented last year to a most worthy recipient, Merl Bridges, who has been a volunteer and stalwart of the Ballarat Support Group for more than twenty years. Our thanks to Sir Zelman and Lady Cowen for personally presenting the award to Merl.

We were saddened with the passing of Don Chipp last August. Don was a great Australian. He worked with us to increase community awareness and lobby governments for improved services and support.

In 2006 we celebrated our twenty fifth anniversary, recognizing the vision and determination of the founders of Parkinson's Victoria. From humble beginnings, we have grown to become the peak body representing the interests of people living with Parkinson's.

While acknowledging the past, we look to the future with firm resolve for significant improvements in services and support for all Victorians.

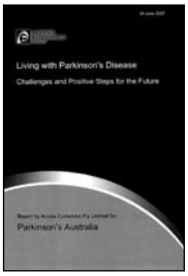
Original and current Board Members celebrate the organisation's 25th Anniversary in 2006

We announced last year that we had commissioned an ***Access Economics Report***. This report, for the first time in Australia, identifies the extent and scale of the costs and disability burden faced by people living with Parkinson's. It was recently launched at Parliament House, Canberra, and was received by Health Minister Tony Abbott.

Key findings indicate the total economic cost of Parkinson's was $6.8 billion dollars in 2005. There were 8,900 new cases of Parkinson's in the same year. This represents, on average, one person being diagnosed every hour of every day of the year. Of those diagnosed, one person in five was of working age.

The report recommends governments invest in services and research to reduce disadvantage, improve quality of life, enable people to remain in employment longer and remain independent, living in their own homes, delaying institutionalization. We will use the report as a tool in lobbying governments for change.

Based on this report, the cost of Parkinson's in Victoria can be estimated at $1.7 billion. At present, we receive only $180,000 recurrent government funding to provide services. This is simply not good enough and must be addressed by state and federal governments.



Living with Parkinson's Disease
Challenges and Positive Steps for the Future
Report by Access Economics Pty Limited for
Parkinson's Australia

Further information on the Access Economics report can be found on page 11 of this report.

Our national secretariat, based in Canberra, has enhanced our ability to influence the Federal Government, and will provide national policy and lobbying that is responsive to the needs of people living with Parkinson's in Australia. Norman Marshall, who was appointed CEO of Parkinson's Australia in May, continues to work to represent the state and territory interests to the national decision makers.

We continue our commitment to research and are pleased to announce a major collaborative research project with the Howard Florey Institute, establishing the Parkinson's Victoria Research Register. This project will commence in the coming year.

We have increased our service capacity and still achieved a satisfactory financial result this past financial year, with a modest surplus of funds. As demand for services increases, our need to offset our shortfall in government funding through fundraising and events continues. Your support is welcome and appreciated. If you are unable to make a donation, please consider supporting us by remembering Parkinson's Victoria in your will, or contributing to our Endowment Fund.

I take this opportunity to thank and acknowledge members of the board, volunteers, our Chief Executive Officer, Glenn Mahoney and staff, donors and supporters for their contribution over the past year. Together, we really do make a difference.

Royce Pepin AM, MBE, GCSJ, Ph.C
President

Parkinson's fact: One in five people diagnosed with Parkinson's are of working age.

Chief Executive Officer's Report

Services

"Parkinson's Victoria is to be commended for the brilliant organization in arranging and conducting this ground breaking workshop in sexuality and disability, an area that needs much more attention. This day inspired those living with Parkinson's, carers and health professionals who were in attendence." Conference attendee.

In a year of significant service development and achievement, the ***Triple S (Senses, Sensuality and Sexuality)*** seminars were a highlight. In partnership with the Parkinson's Social Worker/Nursing Professionals Group, we welcomed international expert, Gila Bronner from the Sheba Medical Centre Israel. Ms Bronner is a trained sex therapist and counsellor.

Ms Bronner conducted workshops for people with Parkinson's and health professionals on the challenges Parkinson's presents in relation to intimacy and strategies to deal with them. Feedback from participants was exceptional, and the number of attendees demonstrated a real need for more information of this type.

Staff from Parkinson's Victoria and members of the Parkinson's Social Worker/Nursing Professionals Group at the Triple S seminar.

Education Services

Education is a fundamental component of our service delivery. Through the provision of seminars for individuals and families, we improve understanding, provide strategies for symptom management and build knowledge of service networks. We provided more than 80 presentations to people with Parkinson's during the past year, including **a regional seminar in Wangaratta** with 120 participants, our annual ***Recently Diagnosed Seminar*** with 120 participants, and various presentations to our network of 46 support groups.

"Recently I have had cause to contact Parkinson's Victoria to obtain information to assist in the management of a client in the community with complex issues. The professionalism, helpfulness and support have been exceptional. Please accept our gratitude for assistance, which will hopefully improve not only the quality of care, but also the quality of life for our client and her family." Nursing unit manager of a low care/ageing-in-place residential care facility in Central Victoria.

This feedback demonstrates the importance of education to health professionals.

We recently conducted a survey asking people living with Parkinson's to identify the main issues important to them that need addressing. Overwhelmingly, the priority issue was improving medication management in hospitals and accommodation centres, and improving the knowledge of community health professionals about Parkinson's.

In the past year we conducted 115 education sessions for community health professionals across Victoria. By increasing ***their*** knowledge of Parkinson's, in turn, the care and medication management of people improves. Major presentations have been made to the *Disability Support Workers Conference, Aged Care Expo attendees, Royal District Nurses, Palliative Care Victoria* and regional hospital nursing staff.

Community Development Worker Catherine Watson at the CareEX expo.

We will continue to advocate for funding to increase the levels of education provided to health professionals across Victoria.

Support Groups

Members from the Bunyip Support Group.

Parkinson's Victoria originated from a support group in 1981. Today we have a network of 46 Support Groups located across Victoria, providing mutual support, friendship, information and awareness in the local community.

Last year, new support groups commenced in Echuca, Charlton, Orbost and Swan Hill. This year we have continued to grow, with groups established in Mildura, Mansfield and Bright. Unfortunately, our St Albans group has closed. However the Essendon Support Group provides a nearby alternative.

Our sincere thanks and appreciation to the leaders and their teams of volunteers who provide this valuable community service.

We conducted two Support Group Leader's workshops during the year, providing both education and the opportunity to meet and learn from each other. Our staff made eighty five visits to support groups across the state.

In 2006/07, we hosted two forums, entitled Respite without the Tears. The forums were aimed at encapsulating the experience of carers of people living with Parkinson's and working towards possible solutions. The report and findings are currently being written up into a report for further advocacy.

We also partnered with the Council of the Ageing (COTA) and Kingston Centre (Movement Disorder Clinic) to deliver a much needed forum on Parkinson's and exercise for fitness instructors.

Parkinson's fact: As the population ages, Parkinson's numbers will double in thirty years.

The education has meant an increase in the specialized staff available to help people living with Parkinson's engage in exercise in the community.

Information

We have responded to more than 4,700 requests for information during the past year. These have been provided via our toll free information line (1800 644189), information packs for newly diagnosed, volunteers and carers, brochures, and face to face visits. Through the generosity of the Michael and Andrew Buxton Foundation, we were able to redevelop our web site, improving navigation, access and content. We average 4,500 visits to our web site each month.

In partnership with Alzheimer's Australia, we produced a DVD and booklet on Lewy Body Dementia. We have received funding from the Trust Company to produce an exercise DVD, and funding form Allens Arthur Robinson to produce a DVD for newly diagnosed that will be available free of charge from neurologists, support groups and Parkinson's Victoria.

We continued our weekly Parkinson's program on Vision Australia Radio 1179AM, networked across Victoria. Channel 31 broadcast a repeat of the popular Parkinson's series, which was again well received.

Our resource library continues to develop through the expertise and enthusiasm of our librarian Anne Atkin, and our popular quarterly newsletter has been revitalized by Marketing Coordinator Judith Mooney, to become ***Signpost*** magazine.

Awareness

Increasing community awareness is a priority. During Parkinson's Awareness Week 2006, Connex displayed Parkinson's posters on the metropolitan rail network. The posters challenged the perception that Parkinson's only affects older people, and were designed by Nathan Stones, a young man with Parkinson's who runs his own graphic design company.

We conducted a seminar on Deep Brain Stimulation with Dr Richard Bittar and Dr Richard Peppard, and welcomed Fergus Henderson, prominent chef from England, who spoke about his journey with Parkinson's and DBS. Professor Meg Morris was guest speaker at our AGM, updating us on her research project investigating Parkinson's and falls.

The ***Get It On Time*** campaign was launched during Awareness Week, focusing on improved Parkinson's medication management in hospitals and accommodation centres. This received national media coverage on the Nine Network and in print media.

We appreciate the support of The Age newspaper for providing free advertisements promoting Parkinson's awareness, with a commercial value of over $150,000 in 2006-2007.

Fundraising and Events

With increasing demand for services and limited government funding, we rely on community support to provide and develop services. We conduct two letter appeals each year, sell merchandise, and undertake fundraising events. We conducted a successful dinner dance/auction at the Calabria Club, and were once again supported by Connex, allowing us to fundraise at the city loop network of rail stations during Awareness Week.

Nerissa Mapes, who was diagnosed at twenty eight years of age, launched Perspectives on Parkinson's (POP) during the year, conducting events to raise funds for Parkinson's Victoria and the Howard Florey Research Institute. We appreciate Nerissa's support, and wish her every success with her fundraising endeavours.

Volunteers

We sincerely appreciate the skills and experience volunteers bring to Parkinson's Victoria. Volunteers coordinate our 46 support groups across Victoria. They assist with administration, fundraising and auxiliaries, and Ambassadors develop Parkinson's awareness in the community. Over the past year, volunteers have given over 7,200 hours of service, conservatively valued at $115,000.

We appreciate and acknowledge Donna Willis, our Administration Officer, who combines her administrative role in a busy office with coordinating our volunteers.

Advocacy

Our Board was pleased to see the recommendations contained in the Lockhart review into stem cell research adopted by both Federal and State Parliaments. Our position statement on stem cell research supported the recommendations contained in the review, with the goal of developing more effective treatments and ultimately cures for a range of conditions.

As well as commissioning the Access Economics Report, we have commissioned a report investigating housing and support issues for younger people with Parkinson's. This is being prepared by Dr Chris Fyffe and Jeffrey McCubbery.

Issues Survey

In the lead up to the Federal Election, we have undertaken a survey of members to identify the issues they would like addressed by political parties.

The six main issues identified were:

- *Improved medication management while in hospital. Nurses in hospitals, nursing homes and respite facilities need improved training and support to ensure people get their medication on time, every time.*
- *Better access to Parkinson's trained health professionals.*
- *Parkinson's education provided to community health professionals.*

- *Increased funding to provide services for people with Parkinson's in regional Victoria, as well as Melbourne.*
- *Improved access to respite care and improved quality of respite care.*
- *Increased funds for Parkinson's research.*

These issues align well with the key recommendations of the Access Economics Report and our ***Ease the Burden*** position paper, developed eighteen months ago. We will use the issues survey as an important lobbying tool.

Research

Parkinson's Victoria has a long history of supporting research. (Page 10 of this report reveals in further detail the research we have supported).

We are pleased to announce a major collaborative research project with the Howard Florey Institute, to commence in 2008. We will be establishing the Parkinson's Victoria Research Register, a cohort of 300 people living with Parkinson's, who will be available as a longitudinal research population.

A rich resource of information will be developed to improve our understanding of Parkinson's. The research findings will be available to research houses in Australia and overseas in future years.

Our staff

I take this opportunity to thank the staff of Parkinson's Victoria, and to acknowledge their commitment and enthusiasm.

Amanda Spillare, our Client Services Coordinator, was recently awarded a Churchill Fellowship to study services and support programs for young people with Parkinson's in the U.S.A. and Europe, with a view to improving services in Australia.

We welcomed Victor McConvey, Parkinson's Nurse Specialist, and Catherine Watson, Community Development Worker during the year. Maz Chowdhury was appointed Finance Officer in November, and Judith Mooney commenced as Marketing Coordinator in March. Together with Donna Willis, our Administration Officer, and Denise Perkins, their contribution is highly valued.

Victor McConvey and Amanda Spillare from Parknson's Victoria and Robyn Gardiner (centre) during the COTA training forum for fitness instructors.

Parkinson's Victoria Ambassadors Program

Nearly every week of the year, somewhere in Victoria, a Parkinson's Ambassador stands up in front of an audience and delivers - from the heart - the story of their personal journey.

In doing so they educate and inform, at the same time as promoting the services of Parkinson's Victoria.

We are truly indebted to this dedicated group of people who often have to travel distances and overcome the usual phobias associated with presenting to a group of strangers.

By Christmas 2007, the Ambassador program will have reached around 1500 people. Occasionally, organisations are moved to donate, but more often they are moved to greater awareness and understanding as they see and hear "real" people living with Parkinson's.

Organisations range from service clubs such as Rotary and Probus, to VCE psychology classes. A highlight was the request from the Prime Life Retirement Company to address their residents in 8 villages across Melbourne and Geelong.

We look forward to the Ambassador Program continuing to reach hundreds and thousands of Victorians with its informative and inspiring message.

Staff from Parkinson's Victoria and members from our team of Ambassadors during the annual workshop.

Peter Raymond, who coordinates the program, would be delighted to hear from anybody who has suggestions of organisations, companies, clubs or associations that may be interested in inviting an Ambassador to speak. Please contact Peter or Donna Willis at Parkinson's Victoria for a presentation or further details.

Ambassador Peter Raymond demonstrates the importance of balance to a VCE Psychology student from Tintern Grammar School.

Parkinson's fact: Parkinson's is second only to dementia as the most common chronic neurological condition.

Abridged Financial Statements 2006 – 2007.

Full audited accounts are available to Members upon request

STATEMENT OF INCOME & EXPENSES

2007

INCOME	$
Government Grants	187,250
Interest	70,714
Products Sales	30,263
Membership Subscriptions	42,538
Donations	107,127
In Memoriam Donations	42,300
Bequests	111,365
Education	10,000
Trusts and Foundations	18,677
Sponsorship	49,270
Asset Sales	1,038
Events	9,507
TOTAL INCOME	**680,049**

EXPENDITURE	
Advertising	5,452
Annual Leave	16.998
Audit Fees	850
Bank Fees	2,300
Computer Consumables	6,213
Computer Maintenance	7,344
Depreciation	15,134
Events	1,404
General Expenses	1,344
Insurance	749
Internet Services	5,188
Equipment	1,361
Education Expenses	157
CARRY FORWARD EXPENSES	**64,494**

CARRY FORWARD EXPENSES	$64,494
Merchandise	19,767
Motor Vehicle	18,455
Parkinson's Australia	24,682
Photocopier Maintenance	1,092
Postage & Courier	14,329
Printing and Stationery	51,403
Public Relations	45
Rent	19,499
Salaries and Wages	309,677
Staff Amenities	1,923
Subscriptions	3,569
Superannuation	20,068
Support Group Expenses	169
Telemedicine Program	5,565
Telephone & Facsimile	15,164
Training	2,260
Travelling & Accommodation	5,672
Volunteer Costs	1,346
Workcare	6,059
YPH Expenses	10,783
Membership Expenses	1,379
Channel 31	3,834
Books & Publications	1,450
Awareness Week Expense	6,430
Facility Hire	10,842
Sponsorship	7,450
Office Expenses	1,165
TOTAL EXPENSES	**628,571**
NET INCOME	**51,478**

STATEMENT OF FINANCIAL POSITION

2007

CURRENT ASSETS	$
Cash	5,682
Investment account	516,630
Endowment Fund	704,256
Receivables	1,686
Stock	6,628
Prepayments	1,347
TOTAL CURRENT ASSETS	**1,236,229**
NON-CURRENT ASSETS	
Plant & Equipment	30,266
TOTAL NON-CURRENT ASSETS	**30,266**
TOTAL ASSETS	**1,266,495**
CURRENT LIABILITIES	
Provisions	17,520
Creditors	57,490
TOTAL CURRENT LIABILITIES	**75,010**
TOTAL NON-CURRENT LIABILITIES	**–**
TOTAL LIABILITIES	**75,010**
NET ASSETS	**1,191,485**
EQUITY	
Members Funds	1,051,037
Research Funds	97,672
YPH Funds	42,776
TOTAL EQUITY	**1,191,485**

STATEMENT OF FINANCIAL PERFORMANCE - YPH ACCOUNT FOR THE YEAR ENDED 30TH JUNE, 2007

2007

INCOME	$
Interest	2,401
Donation	10,000
TOTAL INCOME	12,401
EXPENDITURE	
YPH Expenses	10,783
TOTAL EXPENSES	–
SURPLUS (DEFICIT) FOR THE YEAR	**1,618**

STATEMENT OF FINANCIAL PERFORMANCE – RESEARCH ACCOUNT FOR THE YEAR ENDED 30TH JUNE, 2007

2007

INCOME	$
Bequests	39,690
Donations	2,105
Interest	5,934
TOTAL INCOME	**47,729**
EXPENDITURE	
Research Projects	–
TOTAL EXPENDITURE	–
SURPLUS/(DEFICIT) FOR THE YEAR	**47,729**

Our recurrent government funding represents only 27% of our total income this financial year. We are reliant on donations, bequests and other forms of income in order to offset the shortfall needed for service provision. Bequests of $111,365 represented a welcome addition to our income. While we encourage people to remember Parkinson's Victoria in their will, we cannot rely on this as a regular income stream each year. Our objective is to increase recurrent government funding in order to respond to increasing service demand, and improve our other income streams.

In June 2006, the Board of Parkinson's Victoria established the Endowment Fund with the objective of securing donated funds to be invested for the purposes of capital appreciation and to produce income to support the mission of the organization. This is represented in the Balance Sheet Current Assets as $704,256. The Endowment Fund includes income generously bequeathed from the following:

- *The Helen Sophie Gerstmann Bequest*
- *Mrs P. Di Battista Trust*
- *The Joe White Bequest*
- *The Frances Dumaresq Bequest*
- *The Henry Newell Bequest*
- *The Anastasia Coleman Bequest*
- *The Phyllis Macgregor Bequest*

The 2006-2007 financial year end result was a surplus of $51,478. Our challenge is to build recurrent government income to meet the increasing demand for services, to increase our donor income, to continue to build our membership base, while continuing to monitor our expenditure carefully.

Parkinson's fact: Every hour of every day of the year, a person is diagnosed with Parkinson's.

Parkinson's – It's personal

While statistics about the prevalence, impact and cost of Parkinson's lend weight to our fight for improved support services, community understanding, funding and professional education, the Parkinson's story will always begin and end with the people who live with the condition.

Nerissa Mapes

It all started with a fall on the netball court. I tripped over a stray leg and fell on my arm. My hand was badly bruised and took a long time to heal. Once the bruising subsided, my typing skills didn't return, but I was convinced it would get better with time.

After a while, people began to comment on how slow I was. My moves on the dance floor became limited to a single motion that my friends nicknamed 'the shoulder', and I became famous for my afternoon naps. Eventually, other aspects of my life became increasingly difficult and annoying. Simple things, like negotiating a knife and fork or trying on clothes in a store change room became a constant source of frustration and embarrassment.

It's funny how as a young person, these things really didn't concern me, and I never questioned my body's ability to heal itself. I wasn't concerned when my GP referred me to a neurologist or when the neurologist recommended a set of MRIs.

But it all happened fairly quickly from that point: The shock diagnosis, the dexterity and medication response tests, telling my family and friends.

In the first few months after I began taking medication, the nausea was like being hit by a truck. My appetite disappeared and I had to force myself to eat. I lost a heap of weight, which is sometimes difficult to explain to friends and family, and while my nausea has eased off, thanks to better medication management, I struggle to put some 'healthy weight' back on. But, I do have more control over my body and have returned to both dance floor and change room with a vengeance!

I've found having Parkinson's is like being a member of a secret society. It seems people with Parkinson's don't talk about "it", often not telling friends, family or work colleagues for years, if ever. But I seem to have missed the unspoken ban on communication, though I'll admit it isn't easy to tell people. I find the main problem is that it sounds so dramatic, yet I am not a dramatic person. Added to this is the fact that most people don't know much about Parkinson's, and this lack of knowledge either makes it sound more serious than it is, or as though I have just told them I have a common cold.

2006 was the most challenging year of my life. But I'm pleased to report I've achieved some great things in that time - despite having undergone counselling for depression. I completed the first year of a post graduate qualification, received a promotion, and founded ***POP – Perspectives on Parkinson's*** to raise awareness and funds to help find a cure for the disease in my lifetime.

And, I'm still playing netball!

Nerissa, diagnosed 2006.

Nerissa Mapes, founder of POP – Perspectives on Parkinson's.

Anne Atkin

Isn't hindsight amazing? Once I had a name to put to the changes I was experiencing, so many of the traits that had been creeping up on me fell into place. But at the time, I tried to convince myself that my aches and pains, fatigue and general clumsiness were 'natural' at my stage of life. Mind you, I pursued a lot of answers for my symptoms, and I was (mis) diagnosed with a variety of conditions; fibromyalgia, frozen shoulder, menopause, but Parkinson's never entered my mind – or my doctor's!

While it was a running joke in our family that I would trip over or walk into anything, other symptoms were much … stranger. My left arm wouldn't swing when I walked, my sister commented on how hunched over I had become and the fingers on my left hand would curl into a claw-like fist. Sometimes, as I watched TV, I would realise my mouth was open and I had saliva on my chin. I thought I was losing my mind. I was too embarrassed to tell my GP about all my symptoms, so I just complained about my left shoulder. But finally, almost by accident, a neurologist gave me the ***right*** answer – Parkinson's.

Life in those early months was all about reacting to my diagnosis. After breaking the news to my family, I became voracious in my desire to learn everything there was about the condition. My days were ruled by medication, visits to neurologists and the physical limitations brought on by the condition and medication side effects. And in between it all, I was trying to continue my life as a primary school teacher, mother, wife, and human being!

Since my diagnosis, various symptoms have come and gone and some have simply stayed. Cramps, hot flushes, rigidity, hallucinations and disrupted sleep (which results in a 'foggy head' and leaves me feeling and looking exhausted) all keep me on my toes

Parkinson's fact: More funds are needed for services and support.

as my neurologist, specialists and I attempt to manage my Parkinson's. It seems that everyday brings new changes and challenges.

Slowly, my new life became simpler, better, normal even – or at least a new sort of normal. Parkinson's medication helped reduce the symptoms that had curtailed my independence and quality of life, anti-depressants alleviated the stress and melancholy that were side effects of the medication, and visits to the movement disorders clinic loosened up my rigid body.

In many ways, I think my approach to life, my passion for teaching, my desire to understand the world around me and to help others see the beauty in everyday things, have been my salvation. Today I am an Ambassador for Parkinson's Victoria and spend time as a volunteer librarian for the organization. My husband and I still plan on taking that big dream trip around Australia in a caravan and I've started holding art classes for a local support group.

Being part of the Parkinson's community helps me handle my diagnosis, and helps me to help others in their own journey. I am not ready to think of myself as disabled. Parkinson's has made my future very uncertain, so I need to keep my life as normal as I can, for as long as I can. I say to people who ask, "Yes, I have Parkinson's". But I don't stop there, "I also have blond hair and blue eyes, so see ***me*** first and Parkinson's second. It is something I have, it is not who I am."

Anne, diagnosed 2005.


Anne Atkin indulges in a favourite pastime.

Peter Raymond

When I was diagnosed, my wife and I had to deal not only with our own preconceptions about the condition, but also our children's.

For our son, those three words "I have Parkinson's" suddenly transformed me from the fit, healthy, active, *indestructible* father he knew, to being a mere mortal.

In many ways I disagreed. I understood Parkinson's was a degenerative disease, but it wasn't fatal. And after my diagnosis, I continued to see myself as fit and well. *"My symptoms were not so obvious. No one will notice any difference".*

But in the lead up to diagnosis, the little changes were starting. Over the past decade, I noticed a marked deterioration in strength on my right side, accompanied by persistent shoulder and neck soreness. Some days I felt extremely weary and carried my feet like leaden weights. My balance was not quite as sound and I stumbled occasionally. My hand writing at times became so bad even I could not decipher the spider-like scrawl. I purchased an electric toothbrush because cleaning my teeth manually had become an exercise requiring greater dexterity than I could muster. I even began to shave left-handed.

All these changes were subtle and, at the time, of no consequence. I was simply getting older. That's what older people do. They slow down.

My self-diagnosis was tennis elbow, but eventually after weeks of ineffective physiotherapy, my GP made the correct diagnosis in less than a minute.

After diagnosis, my perception of what Parkinson's was, how it affects you, what the future holds, became very personal. Which is why, when my wife and I attended a Parkinson's Victoria seminar, we asked ourselves "where are all the trembling old people?"

Since then, I've realised that Parkinson's is a multi-faceted condition, and that while there are a number of common symptoms, no two journeys are alike. Needless to say, any idea that Parkinson's instantly means a life half-lived is out the window.

Since that period of discovery and initial fear, nothing much has changed for my wife and I, in our approach to life and the way we live. I retired at 55, which I was going to do anyway, but still work as a management and training consultant. My wife and I travel overseas as often as we can afford and I am planning to play my 40th season of cricket in a few weeks.

However, I struggle to lift and hold my beautiful but wriggly 18-month-old grandson. I fiddle painfully with small change and know my right arm and hand are becoming weaker and weaker. Mishandling cutlery means cold soup and I have become more left-handed in everything I do.

Sometimes I wake at night burning like a furnace. I've developed adult acne. I know the location of every public toilet in Melbourne. I have had to add more fibre to my diet. My calf muscles cramp. I never go to bed before midnight and turn in bed like the Queen Mary! The medication I was first prescribed precipitated out-of-character, compulsive and addictive behaviours requiring counselling and personal determination to overcome.

But, otherwise, I'm actually really fine, and I wait expectantly for what lies around the corner. Not fearfully expectantly.

I just love a challenge and am determined to grow old with my friends and family – and I mean really old.

Peter Raymond, diagnosed 2001.


Peter Raymond during one of his presentations as an Ambassador for Parkinson's Victoria.

Research

Since inception, Parkinson's Victoria has supported a range of clinical and applied research projects to improve the quality of life of people living with Parkinson's. We continue to advocate via state, national and international forums for increased support for Parkinson's research.

Following is a summary of research projects we've supported over the past two decades.

1986 Austin Hospital, Dr's Donnan & McKenzie
Research Program

1988 Brain Bank
Purchase of Neural Tissue Storage Facility, Austin Hospital

1989 Monash Medical Centre, Prince Henry's, Dr's Iansek & Kempster
Movement Disorder and Apomorphine Program

1990 Monash Med Centre

Dr's Horne, Mathers & Love
Research into Bladder Dysfunction in Parkinson's disease

1991 Austin Hospital, Dr G Donnan
Research on Adrenal Transplant to Brain

1992 Monash Med Centre, Dr's Iansek, Phillips & Bradshaw
Assessment of Motor Disturbances in PD

1993 (Monash University), Dr's Jeffery Rosenfeld & E. Butler
Evaluation of possible therapeutic benefit of Sub-thalamic Nuclear Lesion in Parkinson's Hippocampus

1993 Austin Hospital, Dr's G Donnan & D Howells
Role of Neurotrophic growth factors for the recovery of dopaminergic function in models of PD

1995 Kingston Centre
Provision of Kilter Force Platform for Measurements of Movement Disorder

1996 Austin Hospital Brain Bank
Provision of additional Neural Storage facility

1997 Austin Hospital
Research into repair and regeneration of nigrostratal dopaminergic neurons in PD - Dr David Howells

1997 Kingston Centre
Research Program, Felicity Whitworth

1997 Brain Bank, Austin Hospital
On costs in assessments

2000 Walter & Eliza Hall Institute
Drs Trevor Kilpatrick, Elizabeth Coulson and Perry Bartlett into the role, if any, of a particular neurotrophic receptor in the brain in relation to Parkinson's

2000 Mental Health Research Institute (MHRI)
Funding to Maarten van den Busse (Ph.D) for research into neurodevelopmental aspects of dopaminergic function in the brain

2000 Austin Hospital
Research into the continuing investigation into the reduction of neuron growth and survival

2000 Kingston Centre
Teleconferencing procedure to rural Victorian centres including the training of professionals re movement strategies

2000 Parkinson's Brain Bank support

2000 Melbourne University
Research into psychological aspects of brain surgery on patients

2001 Mental Health Research Institute (MHRI)
Continuing research on Neuro-developmental aspects of the Dopaminergic Function of the Brain

2001 Austin Hospital and Melbourne University.
Establishing the nature and significance of recently discovered dopamine neurons in the striatum of people with Parkinson's.

2005 Grant to the Monash Institute of Neurological Diseases

2005 Parkinson's Victoria Brain Bank ongoing support

2005 Eastern Health Pilot Project for Parkinson's Clinical Nurse Consultant

2005 Michael J Fox Research Foundation Fast Track Program

2005 Swinburne University
Parkinson's and the impact on quality of life

2005 Access Economics Parkinson's Study

2007 Parkinson's Victoria Collaborative Cohort Study with Howard Florey Institute

We value your continued financial support to undertake research into the cause, cure and care to reduce the impact of Parkinson's in Australia.

Donations of $2 and more are tax deductible. Donations can be made online, by credit card or cheque to our postal address.

Parkinson's fact: Prevalence is expected to grow by 15% over the coming five years.

Parkinson's Costs Australia $6.8 billion per year

Parkinson's Australia: Challenges and Positive Steps for the Future

Access Economics is one of Australia's leading economic consulting firms, with a reputation for the independence, quality and integrity of its work.

Parkinson's Australia commissioned ***Access Economics*** to identify the extent and scale of the costs and disability burden faced by people living with Parkinson's, their families and the wider community. The report makes recommendations to reduce discrimination, to enable people with Parkinson's to remain in employment longer, continue living at home longer, require less hospitalization and receive better medication management. Investing in improved services, supports and research will impact positively on the rising economic and social costs of Parkinson's in Australia.

Parkinson's is the second most common neurological condition in Australia, but remains one of the least understood in terms of its cause. There is a lack of awareness in the health and general community of the challenges and needs of people living with Parkinson's, as well as community stigma and constraints in the delivery of health and social support services.

Key Findings

Parkinson's is a chronic, progressive, incurable and disabling neurological condition. People living with Parkinson's are confronted with major issues of disability, including tremor (trembling in hands, arms, jaws and face), rigidity and stiffness of limbs and trunk, sudden slowness and loss of spontaneous movement and impaired balance and coordination.

In many cases, Parkinson's results in impaired speech and various mental health issues, such as depression and anxiety arising from both the impacts of the condition on individuals, the pathology of the condition and the side effects of medications.

Other symptoms include sleep disruptions, difficulty with chewing and swallowing, and urinary and constipation problems.

It is conservatively estimated that in 2005, there were between 54,700 and 72,200 Australians living with Parkinson's. This will increase by 15 per cent in the next five years, and will significantly increase with the ageing of the population.

- *One in five people with Parkinson's are of working age.*
- *Parkinson's is more prevalent than prostate, ovarian or cervical cancer, leukemia or multiple sclerosis*
- *Compared with other neurological conditions, Parkinson's has the second highest prevalence and number of deaths, exceeded only by dementia.*
- *People with Parkinson's experience extremely high levels of disease burden. Living with Parkinson's in the initial stages is considered more burdensome than blindness or deafness. Living with Parkinson's in the intermediate stages is more burdensome than primary progressive multiple sclerosis and on par with severe depression. Living with Parkinson's in the final stages is more burdensome than living with disseminated colorectal cancer, and on par with terminal stage cancer or severe dementia.*
- *People with Parkinson's are generally younger than people with dementia.*
- *People with Parkinson's live with the disease for a relatively long time, compared to diseases such as cancer.*
- ***The total economic cost of Parkinson's was $6.8 billion in 2005.***

The Access Economics Report identified key areas for a future national strategy:

- *Timely, accurate diagnosis and cost effective health interventions have the ability to reduce the burden of disease, help people to maintain independence, slow growth in future costs and enhance quality of life for people with Parkinson's and their carers.*
- *Train doctors and nurses in relation to treatment, diagnosis and knowledge of medication and hospitalisation protocols.*
- *Increase access to Parkinson's specialist nurses and allied health professionals.*
- *Increase access to services in regional and remote areas through community outreach teams.*
- *Enhance employment retention.*
- *Improve access to respite and maintain growth in support programs for carers.*
- *Increase funding for ethical research into the cause of Parkinson's, prevalence, prevention and more effective treatments.*

The Executive Summary of the Report concludes by stating that these positive steps would result in greater public awareness of Parkinson's, a reduction in disadvantage, improved community participation by people living with Parkinson's and their families, and would encourage the development of cost effective solutions to improve quality of life. In addition, they would delay institutionalization and slow growth in the total cost of caring for people wit Parkinson's in Australia.

For further information on the Access Economics Report, contact Glenn Mahoney, CEO, Parkinson's Victoria.

Parkinson's fact: There were 8,900 new cases of Parkinson's in 2005.

Thankyou

Parkinson's Victoria gratefully acknowledges the generosity of:

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R Phillips

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Frances Dumaresq
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NJ Wilkinson
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La Trobe University
Melbourne University
Michael J Fox Foundation
Monash University
Swinburne University

Have you considered leaving a bequest in your Will to Parkinson's Victoria?

Your bequest will assist in the provision of services, education, support and information to all people living with Parkinson's and research to help find a cure for this chronic debilitating condition