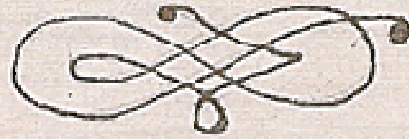
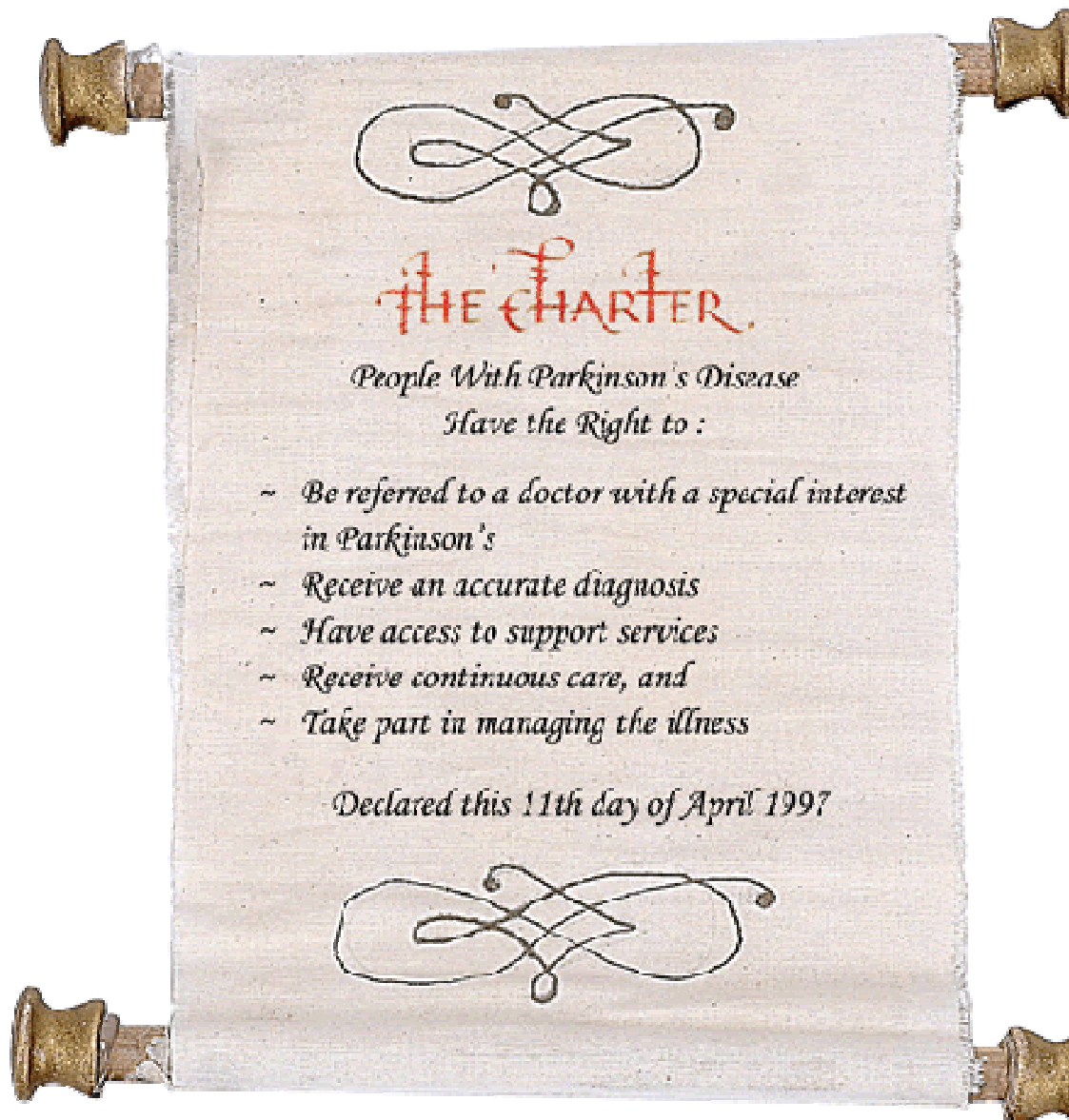




ISSUES SURVEY

2007

- A detailed report of the issues that the Parkinson's community perceive as being the most significant to them currently.



THE CHARTER

*People With Parkinson's Disease
Have the Right to :*

- ~ Be referred to a doctor with a special interest in Parkinson's*
- ~ Receive an accurate diagnosis*
- ~ Have access to support services*
- ~ Receive continuous care, and*
- ~ Take part in managing the illness*

Declared this 11th day of April 1997



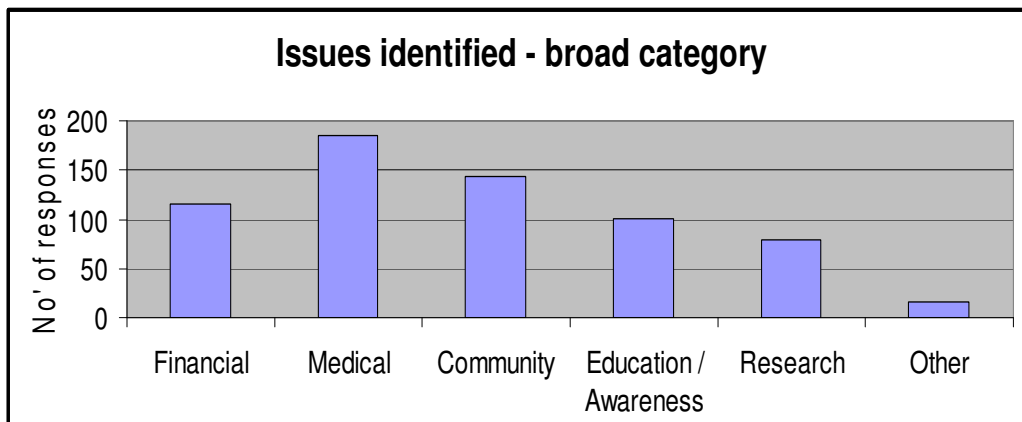
CONTENTS

	Page
INTRODUCTION	
Results of the survey – statistical analysis	1
SPECIFIC ISSUES EXPLAINED	
Financial Issues	2
Medical Issues	11
Community Issues	16
Education and Awareness Issues	23
Research	27
Other	28
THE IMPORTANT ROLE OF PARKINSON'S VICTORIA	29
CONCLUSION	30

In June 2007, Parkinson's Victoria sent its membership an Issues Survey to provide people living with Parkinson's, their carers, families, friends and those with an interest in Parkinson's, to have a say about what concerns them about life with Parkinson's currently and what can be steps can be taken to improve treatment and services and ultimately the quality of life of those 'people living with Parkinson's' (plwp). It is important to remember that the term 'living with Parkinson's' does not simply denote the person with the neurological condition, but also their carers, families and friends who lives Parkinson's will also impact on.

In total, 220 surveys were completed and returned. Responses were completed on behalf of individuals, couples, and on behalf of entire support groups. The qualitative survey provided respondents with the opportunity to identify up to 4 of the leading issues they see regarding living with Parkinson's.

A total of 641 responses were provided through the survey. These were identified as 30 specific issues classed into six main categories.



The **TOP 6** issues identified by respondents were:

1. Medication Management in care – 35%
2. Access to Parkinson's trained health professionals – 34%
3. Education for health professionals – 27%
4. Funding for services to help PwP – 21%

5. Respite Care – 18%

6. Research – 17%

Geographical break-down of responses

61% of all responses came from metropolitan Melbourne and suburbs

39% of all responses came from country Victoria areas¹

Common acronyms used throughout this report

PwP – Person living with Parkinson's

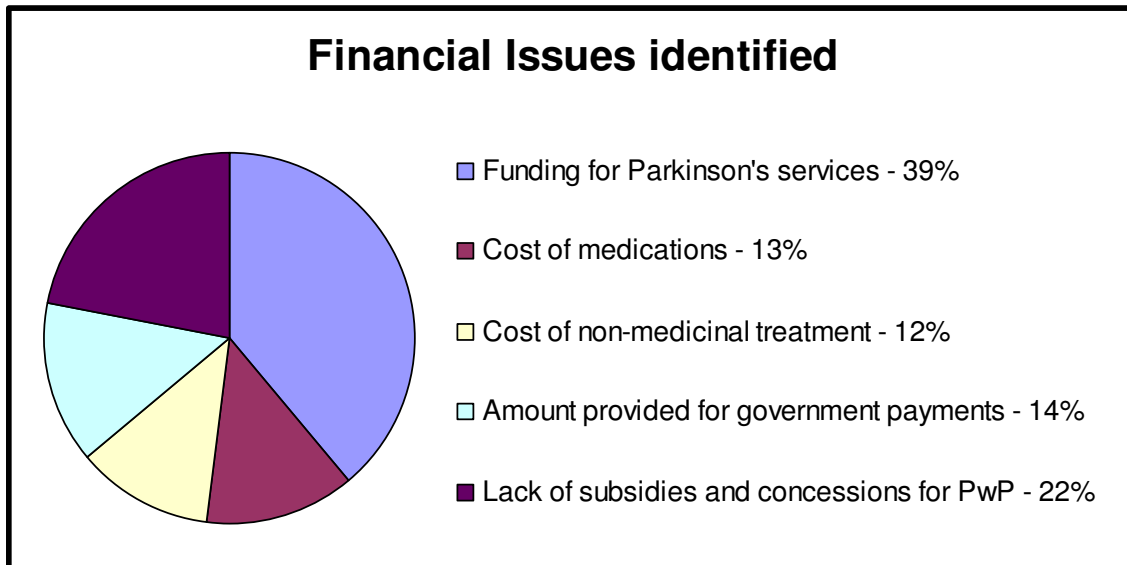
QOL – Quality of life

PD – Parkinson's Disease

¹ According to Australia Post coding

SPECIFIC ISSUES EXPLAINED

Financial Issues



The financial burden of Parkinson's is a significant concern to the Parkinson's community. Half of surveys returned (52%) raised a financial concern as one of their top four issues.

By far the most commonly identified issue regarding the financial strain of Parkinson's related to funding for Parkinson's services. This is an important issue on many levels – many of which will be discussed in detail further in the report.

Funding for Parkinson's services

Identified as one of the overall top five concerns by people who completed the survey, the impact of the lack of current funding for Parkinson's services is significant. Parkinson's services include peak body organisations such as Parkinson's Victoria as well as movement disorder clinics and community programs such as support groups and exercise programs. These are the services where people can get specialised support and assistance in relation to Parkinson's.

The financial benefit of increasing Parkinson's services such as increased education and access to treatments would be seen by the decreasing pressure on the hospital system and permanent care sector. Better support services will reduce the number of people being admitted to hospital (eg. after a fall). Improved Parkinson's services will help to keep people living at home independently for longer, reducing the numbers of PwP prematurely entering residential care facilities. Apart from the obvious QOL issues associated with this, there is significant financial savings to government.

“why do we as Parkies always have to beg the government”

Parkinson's Victoria is currently receives \$180,000 annual recurrent funding to provide services to the 20,000 people in Victoria currently living with Parkinson's². Compared to other neurological conditions, Parkinson's has the second highest prevalence (with dementia the highest overall)³ yet compared to other neurological conditions such as Multiple Sclerosis – who receive funding that equates to over \$1000.00 per person, the amount per person living with Parkinson's amounts to \$9.00⁴

“why is there less funding for Parkinson's Disease as other neurological conditions”

“funding per persons with Parkinson's appears to be much lower per head than most other (conditions)”

Funding for increased Parkinson's services is a general underlying factor that would certainly assist in relieving many of the other issues identified by respondents. These specific points will be elaborated on throughout the report.

“the need for government to pay more attention to the needs of Parkinsonism patients and their helpers. As patients become more helpless, their carers have to give up their jobs, to give more care, or patients may need nursing home care which causes a great deal of financial burden”

Cost of treatment – medicinal and non-medicinal

² Mahoney, G (2006) Ease the Burden report. Parkinson's Victoria

³ Access Economics Pty Limited for Parkinson's Australia (2007) Living with Parkinson's Disease: Challenges and Positive Steps for the Future – 'executive summary'

⁴ Mahoney, G (2006) Ease the Burden report. Parkinson's Victoria

With no cure yet being available to PwP, these people rely on a combination of medicinal and non-medicinal treatments to manage their condition.

Medication is the most common form of treatment available to PwP. It is an effective way to alleviate symptoms. Managing Parkinson's through medications can be quite a complex task. As the condition progresses, the amount of medication required to manage symptoms generally increases as well. It is not uncommon to hear of PwP taking 20+ tablets a day. The cost of obtaining these medications impacts greatly on a person's finances – regardless if they are pensioners with a health care card or if they are self-funded retirees.

Although many of the medications commonly prescribed for Parkinson's are available in Australia and are listed on the Pharmaceutical Benefits Scheme (PBS), there are a couple of medications eg. Tasmar, which some people respond very well to, that are not available in Australia. The personal expense to import these medications that are also not on the PBS can impact immensely on a person's finances – which means a person requiring these medications faces significant expense to receive a treatment which greatly improves their QOL.

The Australian government has a safety net scheme to assist with the cost of medications. For people without a health care card, they have to find the money for \$1059.00 worth of medications before they are entitled to purchase medications at the concession rate. This is a significant difference compared to the concession rate of \$274.40 before qualifying for the safety net⁵.

"Meds alone cost 1/3 of my superannuation pension before the safety net"

Another presenting issue identified in the survey was the frustration of not being able to always access the generic brand of important Parkinson's medications. In particular over the past year Kinson (the generic brand of commonly prescribed Parkinson's medication Sinemet) has been unavailable on a couple of occasions for months at a time. This means those taking the levodopa based drug will need to purchase the

⁵ Department of Health and Ageing. PBS initiatives.
<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/pbs-safetynet-changes>. Site update:
December 2006

more expensive brand – Sinemet at a cost of \$10.12 compared to Kinson costing \$4.90 (price after PBS safety net/concession)⁶, this is an added expense that puts a financial strain on many families.

“Unavailability of generic brand ‘Sinemet’ Proves costly when added to medicines for other complaints”

“Kinson is the generic form of Sinemet and is much cheaper than Sinemet. The current need to use Sinemet has added a substantial increase to my medication budget – I would like to see the price of Sinemet reduced to the level of Kinson when the latter is unavailable”

People who use the medication ‘Apomorphine’ – a Parkinson’s medication administered subcutaneously, receive the actual medication subsidised through the PBS but are left to pay the full cost of the consumables eg. needles and tubing, that can cost in excess of \$200 per month. For those people with more advanced symptoms of Parkinson’s who are appropriate candidates for the surgical procedure Deep Brain Stimulation (DBS), the cost – over \$100,000, means that this treatment is simply not an option for them⁷.

“The cost of purchasing needles, extension tubing and patches for administering medication is approximately \$240 per month. Placing a strain on our finances”

“Have had to pay for all needles unless I went to the hospital like a drug user. Make them free on script for PD users as they are for diabetes”

“Deep Brain Stimulation operations to be fully funded by medicare. These operations can fundamentally change the quality of life for Parkinson’s patients”

“Make Viagra available at a low cost. Parkinson’s has disturbed my sexual function”

In addition to medication, physical therapies can be beneficial in managing the condition. Physical therapies can teach people strategies and help them to move

⁶ Department of Health and Ageing -

<http://www.pbs.gov.au/html/consumer/search/results?medicine=Sinemet> . Site updated: July 2007

⁷ The PBS funds a small number of DBS procedures each year to public patients, but many are still waiting and missing out on this life changing surgery

better and stay safer and living independently for longer. Physical therapies (such as physiotherapy, occupational therapy, speech therapy, etc) are beneficial at all stages of PD with people requiring the services of various disciplines over the course of their life. To access these services privately can be very expensive for those people without private health insurance. For those people who can access these services through community health centres and rehabilitation centres, there are usually long waiting periods for appointments.

In addition to this, many treatments such as massage and other complementary therapies, which many PwP find extremely beneficial, are not subsidised at all (even by many private health insurance policies) which means that they are simply not accessible to many people living with a chronic illness including PD.

“Not enough affordable extra services eg. massage / Physio / exercise groups ...don't know where to go for help”

Many self-funded retirees who completed the survey were unhappy that their money that they had worked so hard to save over their working life, now went to Parkinson's treatment and not on what they worked so hard to save for. In particular, they are upset that they do not receive any concessions or financial support to help them. They are rejected from public services or they are forced to pay the full amount for treatments.

“If Parkinson's is 'incurable' then the requirements to be subjected to 'income/asset' test should be abolished. Parkinson's is not selective in who it chooses so why should those who have saved for retirement be so discriminated against”

For those who are on a pension, the situation is not much better. They are able to access community services for a subsidised price, but the waiting times can be significant and they simply can not afford to purchase private therapy and services – on top of medications, to access the treatment they could really benefit from.

“That specialists doctors be prepared to bulk bill clients who are unable to afford health insurance – for hospital procedures”

Lack of subsidies and concessions

People with Parkinson's face increased living costs when factors such as medicinal and non-medicinal treatments are accounted for.

Half of the respondents who identified lack of subsidies and concessions as an issue in the survey, specifically referred to the lack of subsidies available to self-funded retirees. These are the people who do not receive a government funded pension or health card entitling them to subsidised medications and community services.

Self-funded retirees do not qualify for the MPTP or receive other concessions on bills, etc. that those PwP with a health care card receive. They are often left to foot the full price of accessing services such as the Home and Community Care (HACC) program which would be heavily subsidised for a health care card holder. Self-funded retirees feel that this is an injustice as money that they have worked hard to save is then spent on Parkinson's related costs instead of being put on the things they choose – as would a person without this chronic condition would be free to do. Savings are gradually depleted to a point where they qualify for the pension, which only provides them with the bare minimum of financial support.

“For Parkinson's suffers under retirement age who have a partner full time employed – a health care card and disability pension would greatly assist with medication costs and travel from country to city for specialist appointments”

“Because of the expense involved in necessary aids to assist mobility, our general life in affected reflecting on all family members who need to assist in many cases”

Government payments

In terms of government payments, respondents identified the amount of money provided through the disability pension, aged pension as well as carer payment and carer allowance, as not being sufficient to cope with the added financial burden that comes with Parkinson's.

For many PwP, their condition means that they are forced to take up early retirement. In order for carers to look after the PwP, they themselves are often unable to continue with full-time work. This loss of income and lack of savings and superannuation, means that many PwP and their carers have no choice but to rely on government payments to survive.

“The pension is not enough to live on. Be allowed to work one day per week – without your pension being reduced – my bank account is going down”

“Still have mortgage and work full-time and looking after sick husband and children. Husband on disability allowance even to give up work would be unable to support family”

For someone with Parkinson's, there are the added costs of attending various medical appointments, paying for medications, receiving therapies, paying for aids and equipment as well as for support in the home.

“Living on a pension and suffering with Parkinson's means much of our income is spent on doctors bills / medications / allied health. (I would like) An increase in pension and carer's support, and aids to assist with living with the disease”

“There are a lot of extra expenses - special foods, appliances, taxis to medical appointments, day care, and district nurses, etc. The weekly pay for carers 24/7 is about the same as one parliamentary meal allowance. A gross insult”

Necessary activities of daily living such as using transport become more costly as those PwP who wish to continue driving have to pay to sit a driving test every year to keep their licence. They may even have to pay higher insurance premiums as their diagnosis deems them a higher accident risk. Those who are not able to drive often rely on taxi transport (as public transport is often not suitable), which even with a MPTP card, is still costly by the time one considers the distance often needed to be travelled for specialist appointments for example.

“Transport is not available – too expensive or insufficient. ½ price taxi card should not be means tested”

“Each year I have to be tested for driving ability to retain my restricted licence, and it is quite expensive” “I would like to see driving tests subsidised”

“The enormous expense involved in the aids that have to be purchased. Being on a pension this has limited me in other areas”

Many survey respondents identified the remuneration for carer's as being insufficient. The carer's allowance (non-means tested) provides carers with \$92 per fortnight. In many cases, the costs (direct and indirect) in providing the care outweigh the amount received from the government payment.

“I'm a 24hr on call carer, 7 days a week and find the carer's allowance a bit of a joke”

“Full time carers are on duty 24/7 and deserving greater remuneration seeing that they save the government a considerable amount of money” “The lack of funding from any source is a constant drain on the finances and quite this has to be supplemented from savings”

The significance of the role of unpaid carers is still yet to get the recognition it deserves. Unpaid carers in the community save the government thousands of dollars by keeping the people they care for out of the permanent residential facilities for longer. The caring role is often equivalent to, often greater than, full-time employment and carers should be reimbursed accordingly.

What respondents want done?

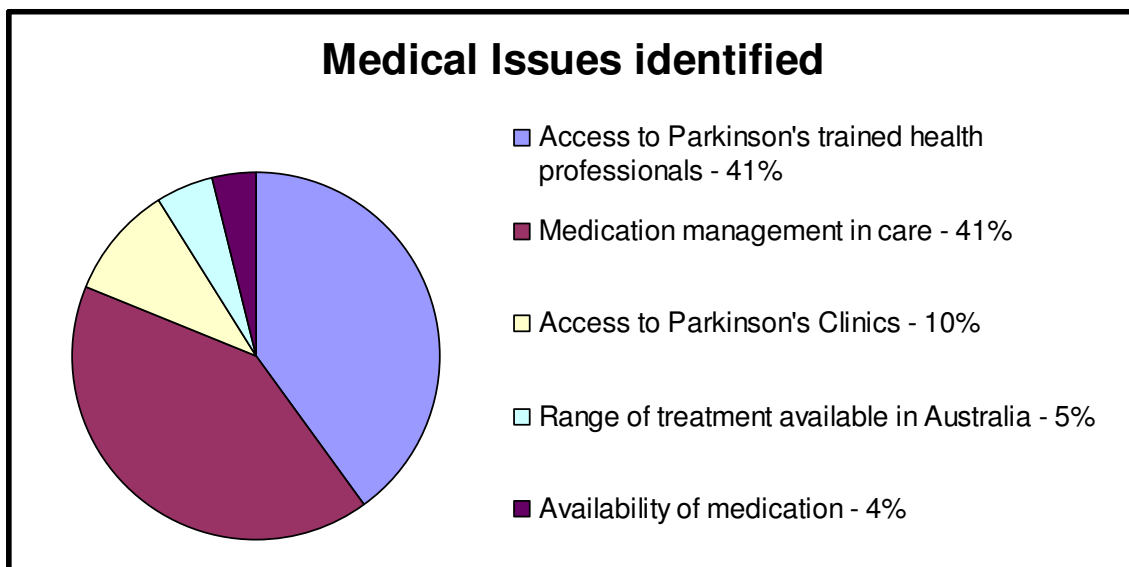
- Subsidies for complementary therapies which can greatly assist general wellbeing
- Re-fund the tele-health service (refer to page x)
- Allow people to work part-time and still receive the pension – they are still contributing to society but not struggling as much financially
- When generic brands unavailable, reduce cost of brand name option
- Make Parkinson's funding comparative with other neurological conditions
- Provide healthcare cards to non-pensioners
- Provide more bulk-billing specialists
- Subsidise apomorphine consumables
- reduce the cost of purchasing aids and equipment

- Subsidise the cost of purchasing medications from overseas that are not available in Australia
- Subsidise the cost of Deep Brain Stimulation so that it is better accessible to all PwP

Medical Issues

Medical issues were by far the most important issue identified by survey respondents. Over 4 out of 5 people (84%) listed a medical issue in their response.

Every person with Parkinson's will be affected differently in terms of the range and severity of symptoms – it is a 'designer' disease! Parkinson's is not seen as a life-ending condition, however in order to prevent complexities that can lead to severe complications proper medical management is extremely important.



Access to Parkinson's trained health professionals

The complexity in managing Parkinson's means that optimal treatment requires the intervention of a specialist in movement disorders. This specialist can provide the most current knowledge about treatment options, and a thorough understanding of medication dosing levels, drug interactions and side effects. This is especially important as Parkinson's symptoms become more severe and complex with the progression of the disease over time. Just over one-third of respondents identified access to Parkinson's specialists as one of their priority issues.

In Victoria, out of all the practising neurologists there are currently only a handful practising who have a special interest in movement disorders. All of these neurologists are primarily based in Melbourne. Many PwP are forced to travel long distances to attend their appointments which can be difficult, inconvenient and in some cases impossible, especially for those who do not drive.

“Country people are being neglected and disadvantaged because medical services in that there is no specialised neurologist practising or even visiting that area” “flights to Melbourne or Adelaide are very expensive added to that are taxi fares to the clinics. Road transport is exhausting and adds costs of accommodation”

People living in rural areas are fortunate if they have any neurologist (not necessarily one with a Parkinson’s specialty) to run a day clinic in their town even on a monthly basis. Although neurologists are the preferred treating doctor over the GP when it comes to Parkinson’s, not all neurologists have the specialist knowledge of the finer aspects of managing Parkinson’s and there can often be consequences with mismanagement of medication dosing levels and contra-indications.

Due to the large demand to see these specialists when they do visit, it can be difficult to obtain an appointment. When a person does attend their appointment, they often report feeling overwhelmed with little opportunity to discuss their questions and concerns. They can be very rushed as well leaving the patients and carers confused and often without having processed the information given to them.

“It is very hard to see a neurologist. They seem to have a very high workload”

Parkinson’s nurses have an important role in providing medical support and assistance to PwP. Although they cannot prescribe medications, they have an in-depth knowledge of how PD affects those with the condition, and they have the time, skills and patient manner to discuss concerns, symptoms and treatments. They can provide practical advice about dealing with symptoms (eg. helping with constipation – a commonly occurring symptom for PwP) and some Parkinson’s nurses are even able to conduct home visits which is very helpful to the PwP who might have difficulty attending a hospital or Parkinson’s clinic.

“Because country areas lack having neurologists who specialise in Parkinson’s disease, we need a Parkinson’s clinical nurse in each country city. It would reduce travelling time and in many cases the clinical nurse who has specialised in Parkinson’s can provide better treatment as less cost”

A lack of Parkinson’s specific professionals means the stories of patients who are being mismanaged by their GP are all too frequent. Without the specialised knowledge patients will often be dosed at medications levels that are too low or high, creating havoc for the patient as they are not finding adequate relief from their symptoms, or they are experiencing severe side effects from too much medication in their body.

All the neurologists with a special interest in movement disorders are primarily based in Melbourne. This is the same for the Parkinson’s Nurse Specialists. Until early 2007 there was a service operating called ‘Telehealth’, which allowed patients from around the regional areas of Victoria to use video conferencing technology to enable a neurology consultation to occur from their local health centre. Unfortunately due the costs of operating this service and the lack of funding from government and private health insurance providers this service was withdrawn earlier in the year. This has left many regional Victorian’s unable to receive specialist medical consultations as they are now left to pay the full cost of \$250 for the consultation, or travel (if possible) to Melbourne for an appointment with a movement disorders specialist.

Telehealth

<<insert a brief description of Telehealth here>> thanks!

“Telelink with a Parkinson’s specialist is now not available to country patients. We have now no contact with our Parkinson’s specialist as the patient’s condition does not allow us to travel to Melbourne for consultations”

(re: withdrawal of telehealth service) “This has very much affected me and my family – as I am not well enough to fly. I have to wait until a family member has come to take me to Melb”

Medication management in care

This issue is the single most common issue raised by respondents with over one-third of people identifying issues of getting their medications on time in hospital, respite or permanent care. PwP often report negative experiences of going into hospital or respite care for one reason in particular – they do not receive their medications on time as prescribed by their treating doctor.

Parkinson's medications play a vital role in the management of Parkinson's symptoms and all medication must be taken on time, every time. The biggest problem is getting staff in hospitals and residential care facilities to be aware that this is the case and to understand that PwP will often need their medications at times that are different to the normal medication round.

"Hospitals appear to have a set time for giving out medications and Parkinson's sufferers most always don't fit in with their timetable and fundamentally go the time limit for medication bringing undue suffering"

Many PwP fear having an inpatient stay in hospital and/or respite care. By not receiving medications as prescribed there is a higher chance for a PwP's symptoms to return. The consequences mean that once the symptoms have switched a person 'off' it takes a lot more time for the body to switch back 'on'⁸. This is most difficult and distressing for the PwP.

(re: hosp admissions) "Each time he changed ward we had to go through the anxiety of wondering how his medications and behaviour/mobility fluctuations would be handled. Some places are more responsive than others"

There was a strong link between respondents who identified medication management in care and the need for better education of doctors and nurses on Parkinson's as priority issues. This has been further explained in the Education and Awareness section (page ???)

⁸ Referring to a PwP as being 'On/Off' – when a person's symptoms are being alleviated they are said to be 'on' and when the medications are not working effectively and the symptoms are present, a person is said to be 'off'.

Access to Parkinson's Clinics

Victoria is very fortunate in that it has 5 Movement Disorder Programs (Parkinson's Clinics) which provide specialist multi-disciplinary care to PwP and their carers.

What are the Movement Disorder programs?

These are clinics – public and private, outpatient and inpatient, that provide medication review and strategy training to help PwP manage their condition better. A patient will may be involved as an outpatient for up to a 6 week period, or in complex situations, they may be admitted as an inpatient for an intense 2 week period for an urgent review of medications and treatment options.

Meds are reviewed by a movement disorder specialist and depending on need, a person may receive therapy from varied allied health therapists such as physiotherapists, occupational therapists, speech pathologists, social workers, dietitians, etc.

Movement Disorder Clinics are available to anyone with a movement disorder (Parkinson's Disease as well as Parkinsonian syndromes) from the recently diagnosed stages right through to the more advanced stages of the illness.

These clinics are found primarily in the south-eastern suburbs of Melbourne. Many people living with Parkinson's are unaware that they exist and many people will live with Parkinson's for many years before being learning of these programs. These clinics offer valuable advice and support to people who have been recently diagnosed right through to those who have been living with Parkinson's for many years, whose symptom management is more complex. The practical skills and strategies that are learnt through these programs are invaluable for day to day management of Parkinson's and compliment proper medication management as a holistic approach to treating Parkinson's.

"I feel I would benefit from access to co-ordinated services eg. a specialist physio, neurologist, GP and eventually an OT and speech therapist. I would like a facility such as Kingston Movement Centre within a reasonable distance"

Parkinson's clinics offer a necessary service to PwP and should be located all through metropolitan Melbourne and in regional centres throughout country Victoria. The education and therapy provided through these clinics could improve safety and QOL

for those living with Parkinson's and provide considerable assistance in helping people to maintain independence at home for longer.

Range of treatment in Australia

With better understanding of Parkinson's and continual improvements to treatments available, it is upsetting for many PwP to know that new and effective treatments exist, yet they are not available in Australia.

The U.S.A and Europe lead the way with treatment developments and it will normally take around two years after release in these countries before Australia will approve use for consumers. This is not to denounce the quality of the stringent regulation process however PwP would greatly appreciate the time lag in approval to be shortened so that PwP are not unnecessarily going without beneficial treatments that can improve QOL sooner.

"Overseas advances in treatments and medications are very slow coming to Australia. We read about alternative treatments or medications that is proving successful but are not able to try it. By the time it is available my condition is worse"

One such example of a medication that is already prescribed overseas is Neupro (Rotigotine) – a trans-dermal patch which provides a stable and continuous delivery of medication to the body therefore smoothing out the medication levels in the blood and reducing the fluctuations in on/off symptoms.

The other issue raised in relation to the range of medications available, are drugs that are available overseas but which have not been accepted on to the PBS here in Australia. These medications therefore have to be imported into the country privately at great effort and expense of the PwP. In many cases, people taking these medications, for example Tasmar (Tolcapone), will make the effort to obtain these drugs because of the significant benefit in symptom relief they receive. They fail to understand why these medications have been approved in many other countries that lead the way in Parkinson's treatment but not in Australia.

“When tasmar was first available, it gave my sister marvellous relief and she was devastated when it was withdrawn because of some small chance of liver damage that she would willingly have risked”

Availability of medication

The availability of medication was raised as an issue in particular reference to a drug ‘Kinson’ which is the generic brand of a commonly prescribed levodopa medication ‘Sinemet’. Over the past couple of years, there have been supply problems with Kinson and on several occasions PwP have not been able to purchase this drug for months on end. This is a significant issue for those taking this medication for two main reasons. The first and most important reason is that although Kinson has the same active chemical component as Sinemet, some people report responding better to the generic brand over the original product. Current thinking would suggest this is due to the different binding processes of the pills which affects the way in which the pill is metabolised once in the body. The second concern PwP have in regards to the unavailability of Kinson relates to cost. As a generic product, Kinson is significantly cheaper than Sinemet so when it is off the market, greater financial burden is placed on those who have to then rely on purchasing the more expensive Sinemet.

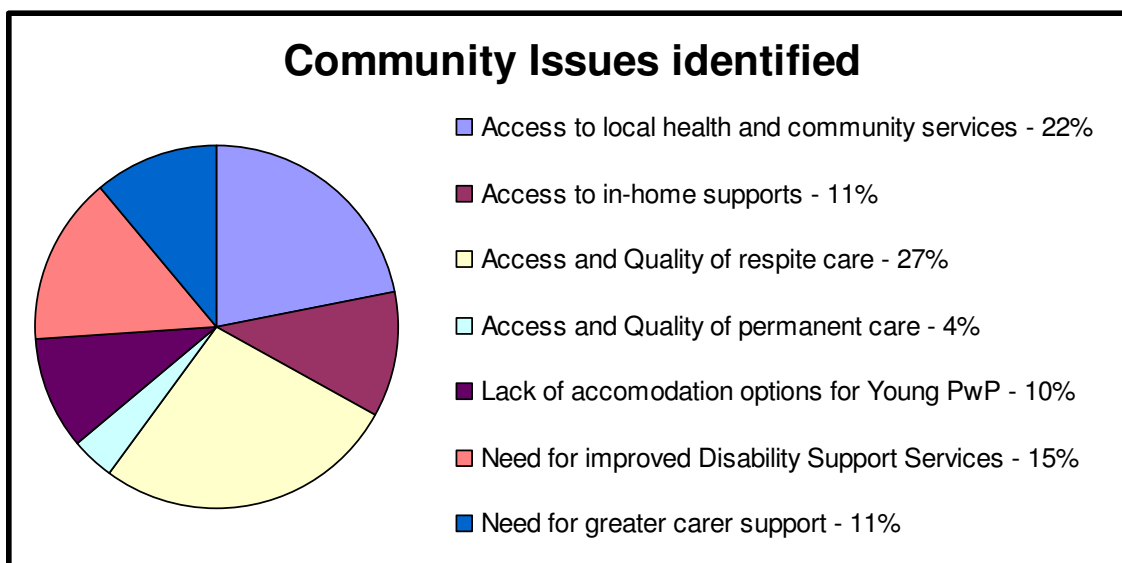
What respondents want done?

- Medications to be given to PwP on time, every time whilst in care.
- For PwP to be able to self-medicate in hospitals where appropriate
- A Parkinson’s support nurse visiting country towns and educating sufferers, carers and other health professionals
- The Telehealth service to be re-funded so regional Victorians can have access to a Parkinson’s specialist
- More Parkinson’s trained neurologists and Parkinson’s Nurse Specialists – in particular ones that can do home visits and that can be placed in regional areas.
- Provide incentives for specialist services to travel to regional Victoria
- Keep Kinson in stock throughout the year
- Consistent and regular staff in hospital and respite care
- Increased education of Parkinson’s and Parkinsonian syndromes
- Ongoing access to Parkinson’s health professionals once placed in permanent care
- Medications that are available overseas to also be available in Australia.

– Medications that have been approved internationally to pass through the regulatory procedure in Australia much faster.

Community Issues

The category 'community' encompasses a wide range of issues identified by respondents. All are important and merit discussion.



Access to local health and community services

In the previous section the problem of accessing Parkinson's specialist neurologist, nurses and clinics was outlined. Taking this point and applying it further to the community setting, many people with Parkinson's who benefit from a range of programs and services such those offered by the local community health centre or by private providers, still have difficulty accessing the services that they need.

Private providers such as allied health therapists through to complementary medicinal services can charge a high price for their services. For those without private health insurance, and many PwP are unable to afford such cover, these services are simply out of reach. Acknowledging that the government has taken a step in ameliorating this situation by establishing the Enhanced Primary Care Program (EPCP)⁹, the ongoing treatment required to be beneficial to PwP means that this program still falls a long way short of being sufficient to meet the needs of PwP.

⁹ EPCP –as part of a patient's care plan, treating doctors can include up to 6 sessions of private health treatment annually, which can be claimed under Medicare

Community Health Centres are a resourceful place to access medical and allied health treatments, health education and multi-purpose groups. The demand for these services can be high however meaning that people can be waiting months to access a service. Those people without a healthcare card may even be refused a service or will be charged the full amount of the service cost. This can be difficult for those who do not qualify for a pension or health care card, but whose financial situation is not strong. 2% of all community issues identified highlighted excessive waiting times for services as an issue – whether it be for a neurologist appointment or a session of hydrotherapy at the local CHC.

The access to services issue continues with the problem that PwP in regional Victoria also have difficulty accessing local health and community services. They might not have the knowledgeable staff based locally on a full-time basis, or they may need to travel a considerable distance in order to access the help they need. In addition to this, the staff that are available locally may lack the necessary knowledge about Parkinson's that is required for the best management. A person therefore needs to trade-off - they face the dilemma between waiting a long time and/or travelling a long way to see specialist or staying locally to see someone with less expertise.

“The speech pathologist in our area has one half day per week to work with adults across all areas. There was a long delay getting to see a speech pathologist and I was not able to access regular reviews”

“Difficulty in being able to see dietician urgently who knows about Parkinson's. Did not get right advice and lost more weight and diet interfered with my medications”

“In our area the well known doctors are not taking on new patients. With houses being built – new residents find it hard to get appointments” “More doctors for country areas. It should not be that people have to wait to get to see a doctor”

A common theme raised in the survey responses was the desire for exercise programs that PwP could access in the community. People are starting to recognise and appreciate the importance of exercise in maintaining muscle condition and co-ordination, especially with a diagnosis of Parkinson's, where maintaining mobility is of utmost importance. Respondents reported having difficulty finding suitable exercise programs to participate in within their local community.

Access to in-home support

The importance of staying at home independently for longer is a significant issue in terms of quality of life for the PwP and their carer. In addition to this, the cost of staying at home is significantly cheaper (in terms of government resources) than placing a person into permanent residential care. Although people are appreciative of being able to receive in-home support services - such as home help and personal care, they struggle with the minimal amount provided and argue that given the caring job is ongoing 24/7 just a few hours of in home support each week does very little to ease the burden.

“Lack of help in the home, 3 showers a week, 2 hrs housework a fortnight and 2 ½ hours to shop is laughable when it’s 24 hour a day care”

In-home support can refer to direct and indirect services to the PwP. Personal care attendants and district nurses can provide personal care duties and in-home respite whilst home gardening, shopping and meal preparation are indirect services that can take enormous strain from the PwP and their carer. Due to the demands for these services, there can often be a waiting period to access them and even once they are in place, a person might only receive a couple of hours of help each week. As the quote above suggests, in a 24/7 caring role, a few hours of in-home help a week barely touches the surface in providing necessary support.

Access and quality of respite care and permanent care

This was one of the top 6 issues identified overall and evidently a major concern facing PwP and their carers. Breaking this result down further, most responses referred specifically to respite accommodation – but there are certainly overlapping features with issues with care in permanent care facilities. Accessing respite can be a major form of support to the carers of PwP so it is important that these services are being utilised, and that experiences are positive so that people continue to access these valuable services.

“My husband has advanced, complex PD with issues of falls, continence, hallucinations, sleep deprivation, etc. Have taken respite... the rest was energising and very beneficial for me”

There are many facets of respite care that concern PwP. These range from availability of respite beds right through to the care received once a place in respite has been secured.

Many respondents raised concerns about the lack of respite beds. This was particularly evident from people in regional areas. They are concerned about what would happen if their carer suddenly became ill themselves and where they would go. For many people, respite needs to be organised months in advanced. This is especially the case if a PwP wants to have some choice in the facility to be attended.

“As yet we have not needed this service but the number of respite beds in our area is so small to get one is almost like a lottery win”

“There is one high care respite bed available in Warrnambool. There is a year's waiting time for this respite, unless someone cancels and you are on the emergency list. Carer has 24 hours, 7 days a week unrelenting care”

Inflexibility of respite duration is another issue as for some PwP, a standard one or two week block is too long for some people to handle whereas a couple of nights would be sufficient to provide the carer with a break without disrupting the normal daily routine significantly. In other cases, people who require a longer stay respite placement may struggle to find a facility that will have a spare bed for the required period.

As mentioned previously in the medical issues section, medication management in care is a major worry for PwP looking to go into respite. Many PwP and carers are so concerned about the management in care that they will avoid using respite services. This means that the carer and PwP do not get a necessary break from each other, increasing the risk of carer burnout. Due to the short nature of the stay, staff do not take as much time to familiarise themselves with the specific needs of the individual respite client. This can mean that the PwP may leave respite with their medication regime all out of order, which initially following respite can lead to a few extra days of discomfort in order to get back into a normal routine.

PwP who have used respite in the past, or those considering it in the future, also expressed concerns about being placed amongst people with dementia, which they found difficult. Generally speaking, PwP do not lose cognitive functioning in areas such as memory, and therefore to put them together with patients who are dementing can be a terribly frustrating process.

“Parkinson’s specific high and low respite care and residential care. After all they have special wards for dementia patients and PD is every bit as difficult to treat and manage”

Accommodation options for younger persons with Parkinson’s

Continuing on the same thought as in the last paragraph, it is inappropriate to put someone who is a young PwP, who might have a significant disability in a facility that caters predominantly for the senior population. There is a movement – Young People in Nursing Homes National Alliance (YPINH), taking place in Australia fighting to fund suitable accommodation for those people who until now have been placed in residential aged care facilities as there was no-where else to live and receive a high level of care. Young people with Parkinson’s requiring respite or permanent care have a strong desire not to be placed in aged care facilities. Specifically built accommodation for young PwP – including other neurological conditions such as Multiple Sclerosis, could be funded to provide a more appropriate option for these people

“(my husband) is always put in nursing homes for respite when he is much younger than the other patients. He is unhappy in care with much older people”

Need for improved Disability Support Services

With Parkinson’s, everyday tasks become more difficult due to the nature of the symptoms. In addition to this, the lack of support for people with a disability in the community can make daily life even more burdensome.

When people find it too taxing to participate in community life such as visiting family and friends, participating in paid or volunteer work, engaging in recreational activities, they risk becoming isolated. This affects not only their quality of life, but can be detrimental to their physical and mental wellbeing eg. increased risk of depression.

“Because of the need to give up driving, our pleasure time into family and our own activities are greatly restricted”

The most prominent issue identified by survey respondents was the difficulty experienced with transport. This is in terms of availability, accessibility and cost. Given that many PwP do not have local access to their treating specialists, transport is seen as a significant concern.

Many PwP find public transport difficult to use and although the MPTP is a good start in assisting those with transport needs, it is becoming more and more difficult to qualify for the program.

“Buses and trains do not think of us. The step is too high and I have to pull myself up with two hands”

“Taxis are too costly when you don’t drive or have a partner. Cant always rely on friends”

“The lack of public transport, i.e. taxis, trains, buses. Isolates me as I don’t have / drive a car”

Disability support services can be broad. They can include helping people with access to facilities so that they are able to engage in community life eg. disabled toilets in public places, availability of disabled parking spaces, access to ramps, lifts, etc. and they should also include extra support to prevent people from facing further difficulties as a result of their disability eg. prevention of discrimination. To further elaborate on the latter point, PwP will often benefit from extra advice and support in regards to legal and financial matters. Issues that younger PwP are often faced with is whether to disclose their illness to their employer. Services such as those helping people with disabilities to stay employed longer benefit not only the PwP but also the community in

general as the PwP is still making an economic contribution and is less likely to depend on government income support as early.

As a PwP's care needs increase with the progression of the condition, their need for support to remain independent at home increases, often beyond what the carer can manage alone. The provision of community aged care packages (CACPs) and Extended Aged Care in the Home (EACH) packages which are managed by a case manager can offer much needed support and access to services in the community. Accessing one of these packages can be difficult with many providers having long wait lists. Community packages will entitle a person to a certain amount of services according to the monetary value allocated to the specific package. Usually only a couple of necessary services can be afforded with this package and a problem that recipients report is that once you are on a community package, you are ineligible from accessing other services in the community - such as Home and Community Care (HACC) or Aids and Equipment programs, which may also be of benefit. This is another example of how understanding the service system can be a confusing and frustrating process for PwP and carers alike.

Need for greater carer support

Carers provide an invaluable service to the community by keeping people living at home independently for longer. Not only are they improving the QOL of the care recipient, but they also take a significant burden off the health and permanent care systems as well.

"My mother at age 80 is primary carer for my father at age 86. Because of his physical therapy there is not much left in the care package to allow her sufficient respite assistance. Mother's mental and physical health suffers"

"I am almost completely reliant on the assistance of my wife in performing my everyday tasks – this has impacted negatively on her health"

Caring for a partner or family member can be a 24/7 job and in order for carers to be able to continue to fulfil their caring role, they need adequate support. Carers need to care for themselves too. Respite services need to be more accessible so that PwP

and carers will be more prepared to make use of them. Currently the system makes it complicated with bureaucracy and some carers have reported that it is more stressful to organise respite than to have the PwP remain at home.

“Recognition of the role that carers play so that respite is more readily available to suit their needs” “24 hour caring is exhausting. My husband has advanced, complex PD with issues of falls, continence, hallucinations, sleep deprivation, etc. Have taken respite... the rest was energising and very beneficial for me”

Navigating the service system can be a nightmare for carers. Due to the requirements of their caring role they do not have the time or energy to be dealing with mountains of forms and chasing up paperwork. The service system that exists to support them will be often be the creator of more stress and hassle.

“Carers need a one stop shop – to deal with Centrelink, State and Federal aged care services, council services, etc. Our whole life – every minute is taken up with Parkinson’s ‘things’”

In recent years, there has been a vast improvement in the support services available to help carers such as Carer’s Australia, Commonwealth Carelinks and Respite Centres, but unfortunately many carers are still unaware that these services exist or what help in the community is available to them.

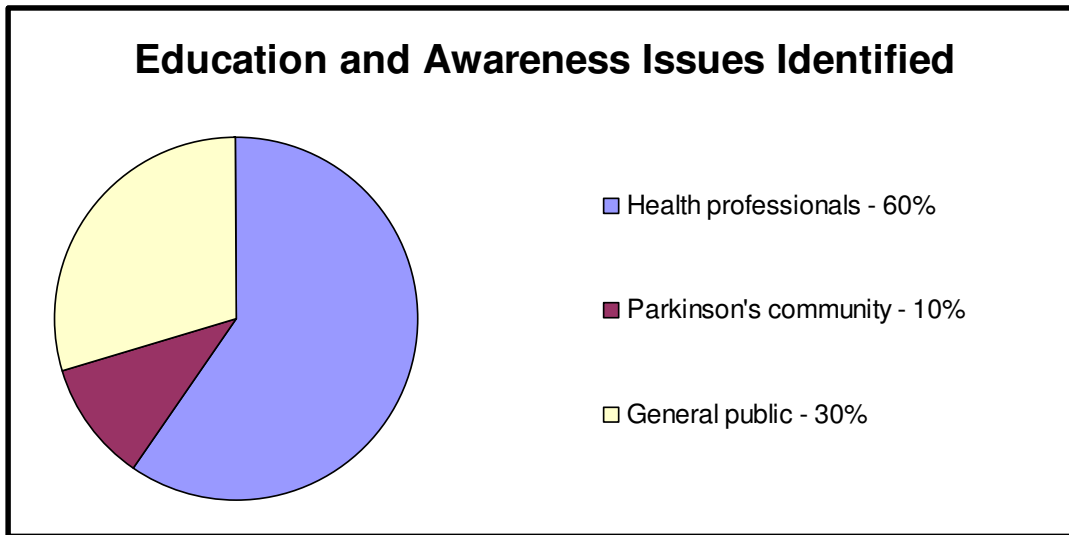
“The government want people to look after their partners. It is very hard for their carers if they don’t get the services”

What can be done?

- Access to exercise programs and hydrotherapy pools
- Funding to help Parkinson’s support groups become stronger to better assist members
- Transport subsidies to get to local community appointments
- Transport subsidies for rural people
- In terms of respite services, providing more beds, more flexibility in arranging respite (eg. length of stay).

- Better access to appropriate residential respite / permanent care that is not linked in with an aged care facility
- Respite that is separate to the facilities used by people with a dementia
- More respite and permanent care beds. Especially in rural areas
- Reduced cost of respite and permanent care
- Make navigating the system less complicated and confusing
- Reduce Centrelink bureaucracy
- Improved disabled facilities in the community such as lifts, ramps, open access areas
- Improved access to disabled toilets
- Better access and availability of public transport
- Make the MPTP (taxi cards) available to everyone with Parkinson's
- Make disabled parking stickers easier to access
- Continue to protect workplace anti-discrimination laws

Education and Awareness



The lack of education and awareness about Parkinson's is still a major concern for almost half of survey respondents. There are three primary areas where this can be improved.

Health professionals

By far the majority of respondents were concerned about the lack of health professionals that had sufficient knowledge about Parkinson's. This is due to the direct impact on the people themselves when they access health services such as going into hospitals, receiving therapy and accessing respite and permanent care.

A common problem that arises when health professionals do not understand Parkinson's is that they are unable to recognise the range of symptoms and how these will affect a PwP. It is not uncommon to hear that a PwP has been accused of faking their symptoms, or as being manipulative. PwP will sometimes receive the wrong treatment such as being wrongly diagnosed as incontinent when in fact the problem lies in them being able to access the bathroom because their medications have not been given on time and their symptoms have returned (they are 'off').

(we would like) "Respect from nursing staff and doctors. Understanding what Parkinson's is. It is not someone on drugs or drunk as people often think and won't help"

Medication management was the highest rating issue to come out from this survey and is strongly linked to education of health professionals. If health professionals had a proper understanding that PwP need their medications on time, every time, then PwP would not be so anxious about going into hospital and respite. The casualisation of nursing staff mean that staff are not getting the extensive experience within specific conditions. This makes the task of education a lot more challenging as training might be held for staff at one stage but a short time later the turn-over of staff means that there is no longer anyone left who received the initial training.

Parkinson's Victoria along with the other state Parkinson's organisations recognise that this is a significant issue for the Parkinson's population and has jointly launched the Get it on Time campaign nationwide.

Get it on Time campaign

As part of Awareness Week in 2006, Parkinson's Australia launched a major awareness campaign titled 'Get it on Time' which focused on the importance of PwP receiving their medications on time, every time. This campaign had already been successfully run in the U.K..

Awareness kits were distributed to all hospitals and health centres and included information about how Parkinson's medications worked in managing Parkinson's and why medication management was so vital in effective treatment.

This campaign continues to be an ongoing effort to increase knowledge about the importance of administering medications on time to PwP.

GP's are often the first point of call when a person starts to notice the symptoms of Parkinson's. Most GP's who suspect Parkinson's will refer people on to a neurologist for further assessment. Some GP's will make a diagnosis of Parkinson's themselves, choosing to also manage the patient's medication regime themselves as well. While a handful of GP's may be capable of doing this effectively, all too often Parkinson's Victoria hears of stories of people who have wrongly medicated. They are either under medicated and are therefore not obtaining maximum symptom relief, or they are over medicated resulting in disruptive and even serious side-effects ranging from

dyskinesia's through to hallucinations and decreased inhibition to pleasure seeking behaviours (eg. gambling, shopping, hypersexuality).

"GPs do not know enough about Parkinson's. Wrong diagnosis! GPs need to be more up to date"

Given the lack of local access of neurologists, especially in regional areas, in some cases it might be necessary for GP to manage a person's Parkinson's. It is therefore important that GP's have a thorough knowledge of Parkinson's, including an understanding of the importance for a PwP to be referred to a Parkinson's specialist for treatment. This is especially important as GP's are often the first contact a person has with the health system when they are looking for accurate information and support.

"Local doctor did not understand enough, when we saw a specialist he doubled the medication straight away"

(re: GP communication) "when told my husband had Parkinson's – no information given – left to cope on our own"

Education and awareness of Parkinson's also needs to be improved amongst all specialisations of health professionals including allied health professionals. These are all people that work directly with PwP and the better their understanding of Parkinson's, the better they are able to target their therapies in an effective, and more importantly, a safe manner.

Parkinson's community

The more the Parkinson's community can educate themselves about their condition and how to best manage their symptoms, the better they will cope with living with Parkinson's and the less the condition will impact on overall QOL.

Many people when first diagnosed with Parkinson's do not understand a lot about the condition. When they are told by their treating doctor that they have Parkinson's, the information that they then receive will vary – depending greatly on how much the treating doctor understands themselves. Neurologists have a very demanding work

schedule which means they do not get the opportunity to sit down with the patient and talk through the diagnosis at length. Even on review visits, the neurologist will focus mainly on medication management for symptom control. To make things more difficult, neurologists will often use medical language that the members of the general community do not understand. Often people will not be told about Parkinson's Victoria or about any service where they can go to learn about what having Parkinson's means and what support is available.

"More seminars on specific elements of Parkinson's and associated developments / problems, should be held – limited understanding of what is happening with layman's explanations"

Education starts at home, and once a person starts to come to term with being diagnosed with Parkinson's they can then start to learn more about the symptoms and treatments of the condition. This gives the PwP, carers and families a certain sense of control over the situation and the way they choose to manage it. Unfortunately there are people in the community who have been living with Parkinson's for years without ever knowing about Parkinson's Victoria and how this organisation can help them. They are unaware that they can be treated by a Parkinson's specialist neurologist and they are unaware that Movement Disorder Programs can be of great assistance in learning strategies to make daily activities easier. They are unaware that support groups meet all around the state and that these groups are a helpful resource for obtaining practical information and advice about living with Parkinson's.

"when my husband was first diagnosed the neurologist he saw didn't explain anything regarding the disease until I took the initiative to ring Parkinson's Victoria myself and with their help I found the neurologist that greatly helped my husband – Thank God for Parkinson's Victoria"

Education for PwP is very important so that they know about medication management, side-effects, contra-indications of medications, how to manage various symptoms and where they can access support. They need to know where to go for help if they have a problem. These are the people who live with Parkinson's everyday. Given that most PwP will see their treating specialist infrequently, they need to be on top of their situation, be the experts of their own body, so that their condition impacts on their QOL as little as possible.

General public

Awareness and understanding – or rather the lack thereof, with regards to Parkinson's in the general community is a significant concern for PwP. In addition to living with the difficulties of medical symptoms, PwP are also battling stigma and discrimination as a result of people not understanding how Parkinson's can affect a person.

Firstly, it is not uncommon for people to dismiss Parkinson's as 'only the shakes'. As this is the most overt symptom of Parkinson's, it is natural that this is the best understood symptom. While some people will dismiss the impact of Parkinson's on a person's life, others will in fact assume the opposite, believing that PwP will develop dementia and that Parkinson's is a fatal condition. Both underplaying and overplaying the effect of Parkinson's on someone's life will affect the way that people react and treat another person on learning they have PD.

This lack of understanding of Parkinson's can lead to stigma – such as assuming a PwP is intellectually impaired, and discrimination in terms of being denied access to certain opportunities. PwP have reported being turned away from venues for presenting as 'intoxicated' due to the fact they may have symptoms including an unsteady walk and a slurred speech. At shops people may become impatient as a PwP may be slower at handling money at the register etc.

"... people older and younger have exhibited impatience and think he is just rude when blocking their way or talking with a low voice"

"Slowly being cut off socially. People seem to think that we can't think"

"Education of the general public to understand that Parkinson's does not render a person mentally ill"

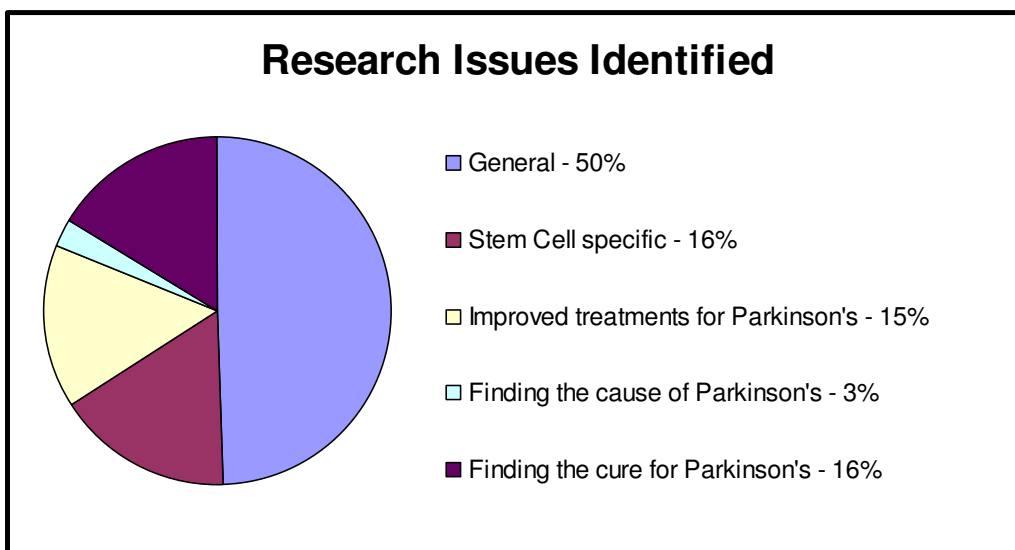
What can be done?

- Education for GP's about Parkinson's and about the need to refer to a neurologist
- More info provided at time of diagnosis
- Better understanding of Parkinsonian syndromes

- Opportunity for a family meeting around time of diagnosis.
- Education in the community service sector – eg. Centrelink staff
- Make navigating the system easier
- Better media coverage of PD and related issues
- Increase knowledge of the range of community services available – for Parkinson's community
- Funding for major awareness campaign to educate Australians on PD

Research

Research is a very important issue for many people living with Parkinson's and their families and carers. Research is the answer to many of their questions regarding the cause of the condition; it provides answers to improving treatment options and it provides hope to PwP for an eventual cure.



General

Half of the respondents did not specify what type of research they wanted to see improved. Ultimately the more that is understood about Parkinson's relating to cause, treatment and cure, the more beneficial it will be to a PwP and the wider community. The main issues raised in relation to research was to see more government funding being put towards Parkinson's research and for PwP with Parkinson's to be made aware of current developments with research.

"Time is running out for people like my husband, who has Parkinson's, which is a progressive condition. We need to feel that at least more is being done"

"Please give our medical scientists sufficient funds to get on with job and find answers. The savings from medical treatment like now would be enormous"

“More money for research into Parkinson’s. I am sad that I will die before the cause of Parkinson’s has been discovered”

Specific research purposes

With regards to those who identified specific areas of research that they would like to see improved, research into improved treatments, finding a cure and research using stem cells all seemed to be on par with each other statistically. Those wanting more research carried out looking into the cause of Parkinson’s tended to be those people with a familial link to the disease, so it is understandable that they want to know if other family members might be susceptible to Parkinson’s as well.

“My cousin and I both have Parkinson’s . The testing would improve knowledge of the condition if present in other family members”

Research that can develop improvement in treatment options is important to PwP as this can improve QOL in the short term, especially as scientists are predicting that a cure for Parkinson’s is still some years away.

“I had to give up my interests when I had looked forward to a happy retirement. Stop postponing the decisions and get moving on our research”

Research using stem cells is the current topical issue when it comes to hope in finding a cure for Parkinson’s. There have been some promising developments to date but stem cell legislation continues to be tightly regulated meaning that research has to meet many stringent requirements. Some of the survey respondents would like to see some of the legal hold-ups reduced as they slow down potential developments.

“Remove all restrictions to stem cell research and speed up research into a ‘cure’ for Parkinson’s. Government restrictions delaying the discovery of a cure. We want treatment of our condition like any other chronic disease sufferer’

What can be done?

- More money invested into Parkinson’s research
- More embryonic stem cell research

- More adult stem cell research
- Decrease the legislation restrictions in regards to research conducted on stem cells
- Keep PwP informed of research developments

Other

Quality of life

Many of the responses raised issues with the loss to the quality of life to the PwP, carers and family as a result of the Parkinson's. Without doubt, the points listed and discussed throughout this report all impact significantly on a person's QOL.

This is why it is important to raise awareness of Parkinson's, to educate health professionals and to increase funding for services and research. Parkinson's does not just affect the people who have been diagnosed with the physical condition. Parkinson's affects the partners, carers, families and friends and many others in the wider community.

Some of the responses from the survey relating to QOL are listed below:

"I've lost my dear husband to Parkinson's. He's still here but not the man I married"
"How can you describe in one sentence. It's a lifetime taken away from you"

"How do you describe seeing someone's independence being taken away from them?"
My life revolves around work and looking after mum"

"I was diagnosed when 55 years (now 75) for the last 5 years – can't talk, cant walk without help. Family life I am just a spectator – hard for them and me"

THE IMPORTANCE OF PARKINSON'S VICTORIA

Parkinson's Victoria is the peak body representing the Parkinson's community in Victoria. Parkinson's' Victoria provides an information, advice, referral and advocacy service to people living with Parkinson's, their carers, families and to health professionals.

PARKINSON'S VICTORIA'S MISSION AND VISION

Parkinson's Victoria promotes the right of all people living with Parkinson's to comprehensive and excellent services which encourage independence and quality of life.

Parkinson's Victoria aims to achieve this by striving to enable every person living with Parkinson's to be fully empowered; to inspire a community attitude change towards Parkinson's; to be the centre of excellence in reference to Parkinson's.

Parkinson's Victoria works to achieve these goals through a number of services

Information line – client service staff provide over the phone information and support. From people who are recently diagnosed to more complex end stage PD issues.

Information kits – containing a broad range of information about symptoms, medications, management, and community support.

Support Groups – There are currently over 40 support groups running throughout Victoria. These are an invaluable support to many people living with Parkinson's and their carers as they can find friendship, support and information from others who are in a similar position.

Ambassadors Program – An important program to raise public awareness of Parkinson's. PwP go out in the community to speak to groups about their personal experience of living with Parkinson's with the purpose of educating people about Parkinson's.

Membership – Parkinson's Victoria offers membership to the public where people can join as a way of supporting the work that PV does as well as research. Membership is

a very important way for PwP to have their voices heard – through initiatives such as this issues survey and report. Members of Parkinson's Victoria are also able to stay up to date with current developments in the Parkinson's community through the quarterly newsletter.

Library – Our well stocked library contains a number of books and DVD relating to PD specific issues. These are a great resource for people to improve their education and awareness about a range of Parkinson's related subjects.

Info sessions and seminars – throughout the year Parkinson's Victoria organises seminars and forums for the Parkinson's community, health professionals, and the general public to increase education and raise awareness of Parkinson's.

Awareness campaigns – this is yet another way of improving awareness in the community about Parkinson's and Parkinson's related issues. Radio and T.V. programs, an annual Parkinson's Awareness Week and various other fundraising initiatives are some of the ways that Parkinson's Victoria achieves this.

“More staff for Parkinson's Victoria – your staff are wonderful. Without help we would not have moved on and made a life with Parkinson's”

“More resources for Parkinson's Victoria – you do a great job. Thank-you”

“When my husband was first diagnosed the neurologist he saw didn't explain anything regarding the disease until I took the initiative to ring Parkinson's Victoria myself and with their help I found the neurologist that greatly helped my husband – Thank God for Parkinson's Victoria”

“I have been greatly assisted by the regular Parkinson's newsletter dealing with the medical issues, but further funding could improve this research task”

“I was under 50 when diagnosed and needed a lot of support but found doctors had little information and Parkinson's Vic is essential”

“Some GPs are loathe to refer people to Neurologists for diagnosis and treatment. Luckily we had obtained information from the Parkinson’s support line and insisted on a referral”

CONCLUSION

The World Health Organisation’s Parkinson’s Disease Charter outlines the standards which PwP have a right to expect with regards to living with their condition with dignity and with the minimum impact to quality of life. Although treatments and support for PwP have come a considerable way in recent decades, there is still substantial ground to be covered in order for the statements outlined in the Parkinson’s Disease Charter to be representative of the entire Parkinson’s community.

There is no better way to gauge the issues that are still facing the Parkinson’s community than by hearing from those who are currently living with Parkinson’s. This report aims to give these people a voice and hope for change.