

**Younger People diagnosed with Parkinson's disease:
Issues in Housing and Support**

'You cope until you can't'

- *Feedback from individuals and carers*

*Prepared for Parkinson's Victoria
On behalf of 'Parkies with a Purpose'
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SUMMARY

For people diagnosed younger, Parkinson's disease is a severely disabling condition as, unlike many people diagnosed in older age, younger people typically live to experience the full spectrum of the condition's debilitating physical and emotional effects.

The impetus for this report came from younger people diagnosed with Parkinson's disease wanting to maintain their preferred lifestyle in a home or community setting. That is, people wanting to receive adequate support from friends, family and services in order to maximise quality of life. The only option they were aware of was residential aged care. For people in their younger and middle adult years (and less than 65 years), residential aged care is widely recognised as an inappropriate setting due to limited attention to wider lifestyle issues arising from the differing requirements of the majority of residents who are aged in their eighties. Further, there have been persistent problems with these facilities maintaining the drug regimes to maximise daily functioning and minimise deterioration.

For people with progressive conditions, medical, health and rehabilitation responses are essential, and service responses extend to planning and enabling many aspects of life within the constraints of the illness, disability and the preferences of individuals and families. For some people this will mean contact with others in a similar situation, for some it will be assistance to continue work or a favourite hobby for as long as possible, and others it will be ways to make new friends or continue participation in some way with daily life experiences like shopping. This ideally will occur in partnership with various specialist services. Younger people with Parkinson's disease described the critical areas for their support as:

- Reliable medication management
- Planned not crisis responses so the individual and carer have a sense of control about the future
- Maintenance of social links and personal interests
- Equipment, technology and adaptations as needed
- Regular attendant support, including way to respond and support periods of fluctuating abilities arising from unexpected freezing and medication 'on/off'.
- Respite which is enjoyable for the individual and planned to complement the carer's and individual's lifestyle.
- The need for services throughout Victoria and not concentrated in some parts of metropolitan Melbourne.

The main issues arising from the project are:

- The distinctive issues for people who have been diagnosed younger with Parkinson's disease are not recognised in the service system and as such this group are 'invisible' in terms of service planning and design.
- The starting point for an appropriate service response for this group is ensuring consistent administration of medication. This must be tackled as part of designing options to solely family or individual-based support arrangements, particularly for out of home living and respite.
- There are no avenues for people diagnosed younger with Parkinson's to explore and plan for their preferred future lifestyle given the stages of the disease progression. It seems this group are very isolated from the service system.
- In common with other progressive neurological conditions, there is a need to build understanding, expertise and pathways between health and disability/community support.
- Younger people with Parkinson's are most likely to be middle aged – not old. This age range is misunderstood or low priority in terms of current program reforms or responses.

The conclusion from this study is that there is a sub-population of people younger than 65 years with moderate to high disability support needs and a much larger group requiring information, emotional support and assistance with longer term planning and services coordination. It is very difficult to identify this group as Parkinson's disease tends to be uniformly treated as a condition of older age and people do not appear to be referred to disability and community support agencies and do not know about them.

The recommendations arising from this project are:

- *Develop a distinct profile of symptoms, support needs, issues and data about younger people with Parkinson's disease in Victoria. Make this profile distinct from issues for older people. This includes:*
 - Undertaking ongoing research and needs data analysis specifically for people diagnosed younger.
 - Establishing a contact point for information and advocacy
 - Providing information about this younger population to health, aged care and disability and community support planners and providers.
 - Develop information and referral pathways between health, ACAS and disability/community support. Review the practice arising from the protocol between Disability Services and ACAS for this younger population.
- *Investigate how to improve the reliability of medication administration, perhaps through the training or standards accreditation agencies.*
- *Identify and provide or negotiate for the types of support likely to be relevant to the different stages of Parkinson's disease, commencing with diagnosis, information,*

counselling and future planning; in home and community arrangements for regular and unpredictable support to maintain preferred lifestyles; information and assistance for family members including in their role as carers.

- Establish an ongoing and proactive case management / coordination role for younger people. Initiate (referral for) lifestyle and needs planning for younger people with Parkinson's disease.
- Trial and assist referrals to disability support services.
- Undertake systemic advocacy about the development of relevant and responsive support for younger people with Parkinson's and their families.
- Trial small scale options for supported community living arrangements.
- *Establish experts in 'navigating the system'* as local resource people.
 - Monitor the effects of timely and earlier referrals as a basis for improved life quality, maintenance of supportive community living arrangements, and avoiding early residential aged care admission through acute hospital episodes.
 - Provide capacity for Parkinson's specific training and materials development.
- *Establish the systemic capacity to undertake these recommendations*, consistent with the systemic advocacy, information and case coordination roles of the other progressive neurological agencies that span health, aged care and disability support service responses.

In summary, the next steps are an initiative to identify the distinct needs of this younger group is needed to clarify what is happening. Next steps could be assisted referral to various disability and community support agencies, as a basis for establishing need and developing initiatives for varied responses to in-home and community living. Parkinson's Victoria has a role to promote issues for this group as a distinct population; and health and disability support services have a role regarding joint potential clients, in common with other neurological conditions.

1. Introduction

1.1 History of the project

Young Parkies Housing Inc. was a group of people diagnosed in their young to middle adulthood with Parkinson's disease. For several years this group was concerned about the lack of housing alternatives for younger people with Parkinson's disease, particularly people living alone or with few day-to-day supports. From their experiences the only apparent option, if home arrangements faltered, has been residential aged care. Young Parkies Housing Inc. recognised the potential for mutual support arrangements or shared housing and have been advocating for community-based housing alternatives which also include specialised staff support to ensure medication, mobility and overall well being are considered and there is support for friends and family members to stay involved.

Young Parkies Housing Inc. disbanded and Parkies with a Purpose has been formed. This project was possible because of funds raised by these groups.

1.2 Project aims

This project aims to raise awareness and understanding of the housing and support issues for younger people diagnosed with Parkinson's disease. The specific project aims are:

- To identify issues and gaps in relation to accommodation (housing and support) and respite for younger people diagnosed with Parkinson's disease. There may be different issues arising for example, for people younger than 50 years, and those of working age (ie less than 65 years).
- To identify the impact on carers in relation to accommodation and respite for those they care for who are people younger than 50 years, and those of working age (i.e. less than 65 years).
- To develop a report which can be used with government, particularly disability support services, as a basis for recommendations to respond to unmet need and other issues identified.

1.3 Method

Staff from the Parkinson's Victoria and Movement Disorder Clinic (Kingston Centre) guided the project. The following individuals and groups were suggested for the information gathering stage of the project. Interviews and discussion groups occurred between May and August 2007 with:

- 'Parkie's with a Purpose' general meeting, and followed by a smaller group and individual discussion with individuals and carers
- 'Experiencing Parkinson's Group'
- Young Parkie holiday participants feedback
- Bendigo Parkinson's Support group

- 'Respite without tears' Carer group
- Phone discussions with younger people with Parkinson's
- Various professional workers from the Kingston Movement Disorder Clinic and Parkinson's Victoria staff.

Several reports were used for reference and are referred to in this report:

- *Access Economics (2007) Living with Parkinson's* – a national analysis of the economic and related implications of Parkinson's disease in Australia
- *Parkinson's Victoria (2007) Issues survey* – feedback from individuals with Parkinson's and carers about their priority concerns and issues
- *Fyffe (2002) Degenerative conditions scoping report* – a report to Disability Services Branch, DHS outlining issues in services development and coordination for people with progressive conditions, including younger people with Parkinson's disease.
- *My spirit still sings – an inside look at the challenges of young onset Parkinson's (2001)* – a series of personal accounts collated by Young Parkinson's Housing Inc.

In addition, the project team identified a small group of service providers for preliminary discussions about service access by younger people with Parkinson's. These discussions were not intended to be comprehensive.

- Aged Care /ACAS managers;
- Darebin Community Services Manager;
- Coordinator, Northern neurological project
- Various central and regional DHS disability services staff
- Linkages coordinator Nilimbik CHC;
- CEO Knox Community Health; Monash CHC;
- Carers Victoria

1.4 Structure of report

The report is in five sections:

- Introduction to the project and how it was undertaken
- About Parkinson's disease in relation to people diagnosed younger
- Findings from discussions with people diagnosed younger with Parkinson's disease and their family member/carers; and with service providers
- Discussion of the findings and issues arising
- Conclusions and some suggested next steps

Words in italics are from interviews or *My spirit still sings* (2001).

2. Experiencing Parkinson's disease as a younger person

Sources for this section: Parkinson's Victoria staff; Fyffe (2002); Access Economics (2007): My spirit still sings (2001); interviews; Vincent McConvey's paper (Parkinson's Victoria)

This paper is concerned with those people with disability support needs who are younger than 65 years. Parkinson's disease usually affects people older than 50 years; however, people in their 30's and 40's are diagnosed with the condition. For younger people the disease tends to be more aggressive and is significantly disruptive to people's lifestyle. The aim of this section is to give an overview of Parkinson's disease and the issues for younger people. There are descriptions from younger people's experiences of Parkinson's disease and the effect on daily life as the symptoms and drug side effects escalate. The following are general trends and there will be individual variations.

Parkinson's disease has tended to be thought of as a condition of older age. However, for a significant population of the Parkinson's disease people, this is not the case. It is a progressive illness with associated increasing disability. It is not a direct consequence of ageing.

Parkinson's disease is considered to involve five stages of progression. Medications become less effective over time and begin to have their own disabling side effects. For people diagnosed younger it is a severely disabling condition as, unlike many people diagnosed in older age, younger people typically live to experience the full spectrum of the condition's effects.

2.1 The need for information, counselling and planning

Few disabling physical symptoms are reported for people younger than 50 years as there has been little disease progression by this age. Stages one and two commence with usually minimal or no functional impairment and progress from unilateral to bilateral or midline involvement without impairment of balance. Symptoms include tremor of one limb, changes in posture, locomotion and facial expression to posture and gait being affected.

However, diagnosis initiates significant effects for the individual and family. Individuals and families at this early stage experience distress and grief, depression and strain on changing relationships; growing financial uncertainty as work capacity is reduced; and wider changes as likely limitations to lifestyle are foreshadowed, such as ability to undertake parenting, recreation and activities of daily life. Support needs at this stage relate to specialist information about the disease, medication, long term implications and health, disability assistance; emotional support and counseling for all family members; and longer term planning, including financial planning and exploration of (future) support preferences.

People are adjusting to taking medication for the rest of their lives. The medication regime comes to dominate the pattern of daily life, while knowing that medication too will have debilitating physical side effects in the future. Information, monitoring and advice about medication are critical as people's anxiety about the future may encourage over medication, which may precipitate psychosis. People will vary in how information and advice is best offered.

'I am ambivalent about being a member of a support group and being reminded of my future disabilities.'

Younger people's life stage requires flexibility of service responses not needed in the same way as for older people. For example, regular appointments such as therapies need to be sympathetic to either individual or partner/carer work or study commitments, and child care requirements.

2.2 Growing need for physical and emotional assistance

The major physical impacts of early onset Parkinson's disease occurs over five to ten years after diagnosis. Stage three involves the first signs of postural instability; significant slowing of body movements; the person has some restriction of body movement but is capable of continuing most aspects of independent living. As time passes the drugs become less effective – side effects include dyskinesia, rigidity, slowness of movement, loss of balance, and digestive, cognitive and speech problems. It is now that medication side effects and disease progression begin to have a major impact on daily life and the capacity for independence.

There is a progressive negative effect on the ability to maintain employment, parenting roles, relationships, driving, community pastimes and interests, and physical, emotional and financial independence. People may experience additional symptoms (such as depression, incontinence, sexual difficulties, swallowing and chewing difficulty, speech changes and sleeplessness). There are significant issues of psychological adjustment, financial loss, need for house modifications and the challenge of the spouse asked to be (often assumed to be) 'the carer'. There are surgical options at this stage too to minimise symptom impact. However, these are costly, results are mixed and the efficacy over long periods remains uncertain. Such surgical interventions are not a cure but an option of a few more years of improved quality of life and mobility.

The disability and effect on daily life are now increasingly apparent.

'Something changes after ten or so years'

There is increasing physical dependence, social isolation, depression and despair.

'You become a different person and rely on someone else for many routine requirements.'

Relationships become strained or breakdown and people become 'socially outcast.'

'It is a socially embarrassing condition for many people.'

The spouse or partner is now being referred to as 'the carer', signaling a profound change in the relationship. The individual has probably left work. Loss of mobility requires cessation of driving with reliance on others or taxis for transportation. Dietary changes are needed to support changes in swallowing. Contenance problems begin to develop. Body language doesn't truly transmit feelings. The ability to express both orally and emotionally has declined.

'I'm not sad – my face is losing its expression.'

Housing modifications or a move to a more suitable home occur. The person has movement so house modifications may not be major, for example, taking off the shower screen. The physical effects become more intrusive in daily life.

'The medication seems unable to control the symptoms and there can be hours of physical pain, either in uncontrollable tremor in a rigid body or painful contortions.'

2.3 Daily assistance to maximise quality of life

Stage 4 involves severely disabling symptoms of limited walking, rigidity, bradykinesia where the individual is markedly incapacitated and is unable to live unsupported. For many they cannot live alone without assistance, or fear living alone. The person now has to live with constant symptoms as treatment options are exhausted. This is characterised by falls, freezes, inability to roll over; and a daily schedule dominated by medication 'on/off' effects.

'As time passed, the on/off from the drugs was getting more – my strange behaviour from sitting like a statue to wriggling as if on an ant nest.'

It becomes harder to leave the house alone.

'I am nervous going out alone. The last time I came home alone I turned 'off' after getting out of the taxi and couldn't unlock the front door.'

These descriptions depict a high level of disability which is daily but unpredictable as the person is 'on' briefly for a short functional time where activities of daily living are possible if there is support.

'I do the cooking in the day, bit by bit, when I am 'on' – but it is often finished by my husband or son if I turn 'off'. I may have to be fed or just my arm jolted if I am 'off.'

The variations caused by the on/off symptoms on an hourly basis make it very difficult to plan, enjoy and participate in normal forms of daily living and recreation.

'My husband has to undress me most nights, help me to the bathroom, and then get me into bed. In the morning I wake up stiff and unable to get out of bed or to the bathroom without help. It takes about 45-60 minutes for the first lot of medication to kick in most days and I can shower and dress myself.'

Other people don't understand the sudden on/off change – *'I can walk in, then I can't walk out.'*

Pressure care issues can arise. There is the risk when moving of falling and assistance and supervision accompanies all movement.

Concurrently, there is reduced ability for planning, organising and problem solving, together with growing difficulty keeping up with conversation, requiring, *'one thought or task at a time.'*

The person's support needs are likely to be greater than family members can manage alone over each twenty four hour time period. Someone needs to intervene to facilitate medication, to stop frequent unfreezing or falling; to monitor dyskinesia (large motor movement) such as difficulty staying on a chair, the bed or with eating). Meals and other activities of daily living become *'a moving timetable'* as drugs are less effective. For many family members there is the ever present state of stress and fatigue. An absence of planned supports historically has contributed to a build up and crisis resulting in residential aged care placement.

'Without my spouse I would need a live-in carer.'

2.4 End stage Parkinson's disease

Stage 5 sees physical wasting with loss of weight and muscle mass due to the disease. The individual is restricted to bed or a wheelchair unless aided. Younger people have been most likely to end up in residential aged care if social structures collapse, as there have not been more suitable 'out of home' and community-based accommodation support options. There is some evidence that moving to residential care and disruption of medication can prematurely trigger the commencement of the end stage of Parkinson's disease.

2.5 How many people?

Younger people diagnosed with Parkinson's disease are a significant sub-population of the overall condition. It is estimated by Access Economics (2007) that:

- Approximately eighteen percent of the population of people with Parkinson's disease are of working age, about 10,000 people nation wide.
- About 80 percent of this group are experiencing stages 1, 2 or 3 of the condition.

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- About one quarter to one third of younger people have moderate to high needs now (stages 3, 4 and 5) and the remainder who will have high needs over time and many of these probably will be within the younger age range.

This project did not include identification of numbers of people younger than 65 years in residential aged care, although it is unlikely that there are (many) people aged younger than fifty.

3. Findings from interviews

This project was initiated because of reports from younger people with Parkinson's and their carers that (residential) aged care was not the preferred alternative for people with longer term housing and support requirements. However, individuals and family members didn't get assistance to maintain and plan for other living arrangements. The project team assumed from preliminary discussions, that in common with other people with progressive neurological conditions, people's support needs would mean they would be involved with a range of health, disability and community-based support services and that timely provision of these supports would reduce or delay the need for higher cost alternatives.

The following comments about service pathways are preliminary. None of the findings can be treated as covering all options, but do reflect consistent trends between reports from service providers and individuals.

3.1 Lack of timely or sufficient information

Consistent with the starting point for the project (described above), there was no indication from people of reliably receiving timely information, or planning and assistance to the individual and carer, including but not limited to, various forms of respite. Over all, individuals and carers were not knowledgeable about the service system and what was possible; let alone what it is called or how it is funded. There was confusion and uncertainty about entitlements for allowances for individuals and carers.

Very few people described having a case manager for planning or the provision of basic information. There was no single contact point described where people could get information about the service system overall. The service system is more complex for progressive neurological conditions where acute, sub-acute, aged care and disability, carer and community support, as well as local government and Centrelink, may all be relevant to an individual's support requirements and their family. Most staff interviewed didn't know the inter-relationships between all of these parts of the service system.

There was no information identified for people who do not speak English.

3.2 Under developed pathways to services

Coordination of referral pathways post initial diagnosis is reportedly complicated as diagnosis is undertaken by a range of neurologists and general practitioners. While some neurologists are linked to the two movement disorder clinics or Parkinson's Victoria, there are no coordinated pathways for people to receive information about community-based supports post diagnosis.

Many people manage their lifestyles with information and medical management and may seek advice at key points of loss of independence such as loss of license, job or relationships. No one described systematic or whole of life planning. As the effects from Parkinson's disease increase, there was no preliminary evidence gained that younger people with Parkinson's systematically use Linkages, Community Health Centres or Disability Services, although there were occasional 'one-off' examples, such as for equipment or case management. This suggests that often this group do not have a case manager, another typical mechanism for services coordination, advocacy and access.

A further assumption described is that if people have higher support needs and are aged 50-65 years, *'there are seen as aged care.'* Younger people with Parkinson's are reportedly referred to ACAS and there were reports of some access to EACH and CAPS packages. ACAS may consider Parkinson's 'early ageing' and therefore may not refer to, for example, to Disability Services Division. Other explanations were also noted, such as individuals are not keen to be identified as having a disability; they may be working for as long as they can and are not interested in the future yet; or find accessing services confusing. Younger people rarely reported being referred to Disability Services and, if referral did occur, they felt the rate of response was slow. The Kingston Movement Disorder Clinic was an important service for some people, which only reaches a part of the total population of younger people with Parkinson's disease. Younger people were reportedly ineligible for HACC if their partner is working.

All services indicated it was difficult and complex to know, and therefore effectively link, people to the wider health and disability support system. The role of Parkinson's Victoria as a phone based service for information limits its services coordination and pathway clarification role as it does not undertake assessment and referral. It is suggested that many younger people with Parkinson's don't receive information about service options on diagnosis. It is believed that a high level of carers/ family/ friends give up on 'the system' until a crisis because *'it is no help'*. There were no systemic advocates reported for younger people diagnosed with Parkinson's disease whose role is to assist people to navigate the service system.

3.3 Triggers for out-of home placements

Lack of home-based support was judged to contribute to more frequent hospital admissions. An acute hospital episode is likely to be the trigger for placement in Residential Aged Care. People with no or little support at home are more likely to experience disruptive unplanned events, (such as, extra falling, non motor symptoms including aspiration pneumonia) and end up in an emergency department, then to inpatient and an ACAS assessment. If the carer says *'I can't take this person home'* or the person cannot be at home unsupported, this may result in referral from acute hospital to residential aged care or a sub acute stay for symptom

control. Some younger people may move to Supported Residential Settings but only those with low level symptoms. This pattern is familiar and has been identified for people with other acquired or progressive conditions.

There was no supported means described for planning for the future living arrangements preferred by individuals and their families. A pattern was described of out of home placement precipitated by crisis. Current options in residential aged care do not suit younger people with Parkinson's disease due to people's life stage requirements and the effects of Parkinson's disease, in particular the requirements for the medication regime. Respondents persistently described how hospital or residential aged care admissions resulted in a lack of continuity of medications (for example, hospital locks up the medication or changes the medication regime; or won't help with administration of medication when person can't do it independently) contributed to greater symptom instability, increased distress and reduced independence. Many examples were given of how the disruption of the timing or the mode of administration contributed to a worsening of symptoms, from which the person may not have recovered. Deterioration can occur quickly as symptoms affect verbal and non verbal communication, often requiring rescue intervention by a neurology specialist.

3.4 Routine and unpredictable support

When people's support requirements were explored, it was found that support is needed on a regular basis (for example, attendant care support for getting up in the morning, assistance with meals, going shopping, administration of medication) and for the unexpected (for example, unexpected freezes, illness, falls). This includes day times hours and overnight, home and in the community. It was the unpredictable nature of people's support requirements that concerned individuals and carers the most.

'There is the fear and reality of falling, at least daily, or being stuck – frozen – in public.'

Medication is required frequently over the day and night, for example, two hourly administrations which must be on time. Some people with Parkinson's are unable to self administer due to constant or episodic physical restrictions or cognitive changes in planning and memory capacity, increasing the monitoring role undertaken by family members. Individuals and carers stressed the importance of reliable administration of medication to minimise physical symptoms and deterioration.

'Unless staff are knowledgeable about the medication regime they make things worse.'

Ideally people wanted assistance from mobile specialists, especially nurses, regarding medication. This would also assist with quick and reliable answers to medication queries. This

is not available in current community support arrangements, where the *'RDNS can't arrive on time.'*

The importance of ways to reduce social isolation and continue with purposeful activities was stressed. People were isolated through their reduced mobility, living alone, living in rural communities and culturally and linguistically. People who had lost their jobs or their partners were especially vulnerable. For some people, but not all, reducing isolation means the chance to get together with other people with Parkinson's of a similar age.

'We understand each other best.'

'Parkie's only holiday – great idea to get together.'

'It's very difficult for younger people to be part of groups with older people.'

Other ways to reduce isolation and increase information availability, such as chat rooms, were of interest, often particularly for carers.

Parkinson's Victoria has expertise, but not the state wide capacity, to undertake or strengthen this range of information and support roles.

3.5 Support for carers

The demands of the unexpected or unpredictable support requirements arising from Parkinson's disease are taxing. Currently partners/ family members undertake the support roles *'until they can no longer do it'*. Carers discussed employing and further training for carers as a way to increase control and decrease variation in medication administration. Family/carers *'have more experience than staff'*, therefore better training for family/ carer about medication, first aid and *'what to worry about and what not to'* would be stress reducing. Carers want *'relief from 24/7'* but said that *'little precedes respite in residential aged care'*. Such reliance on carers reduces the quality of life of carers as well (for example, regular commitments or social engagements are disrupted), especially if there are no options for a 'break.'

Individuals and carers understanding of respite was limited to 'a break' for the carer and frustration that this didn't also guarantee a pleasurable or stimulating experience for the individual. Respite in people's minds meant residential aged care. There was little expectation from carers that respite would be enjoyable for the individual and the lack of something to do for their family member was often the reason respite was disliked. Carers were distressed when the respite experience was distressing or not interesting for the individual. Such experiences meant the home environment was strained when the individual came home from respite.

None of the respondents had experience with in home or overnight respite or other flexible approaches which understood life stage issues (for example, childcare) or the need for both rapid and planned responses. People wanted to be able to plan regular respite experiences, *'not to be told when and how respite would occur'*. It was described that a residential aged care setting may ring *'at the last minute'* to say a bed is available for respite, *'but how can I (carer) plan what I want to do?'* Varied forms of respite were not described, such as when a support worker was available, for example, so that the couple could both enjoy a social outing. There was little recognition that efforts to continue the social, recreational or vocational interests of the person with Parkinson's have the potential to create a 'respite effect'.

Carers described being told *'you will need residential aged care in the future'* and the message being *'just hang on until you can't'*, or use the system for respite even though the person doesn't like it, nor does the carer, and medication is disrupted. The main message was be sure that *'you are in the system'*.

3.6 Limited exposure to options for housing and support

Individuals did not look ahead favourably to the only option they could imagine of *'having to live in a nursing home'*. There were limited examples of planned or preventative support or earlier responses. The carer *'gives up'* with too much physical exhaustion, interrupted sleep and no respite from, for example, getting the person to and from bed and to the toilet.

During the interviews, younger people with Parkinson's disease had few ideas about possibilities to maintain housing arrangements and were unaware of how they could be supported in their own homes, or even shared community living arrangements. The lack of information about other approaches was summarised when some individuals described their ideal living arrangements as:

'Perfect nursing home – age related, Parkinson trained staff, allied health component.'

Ideas related to developing mutual support groups of people living near by or house mates providing support for reduced rent were greeted with interest. There was little discussion of how to design accessible, enabling and safe living environments. It was not clear whether this was because it is less of an issue as many people are mobile, or the nature of the physical limitations did not create an access issue. There was no mention, for example, of alarm systems for falls, on-call attendant systems or dog-assist. Other possibilities for support were not familiar to respondents. Examples explored included people linked through telephone or chat room; linking small numbers of people who live near by as options for people spending time together with a common interest; giving one carer the chance to for example, get out or share the caring role.

4. Discussion of issues arising and next steps

This section outlines some of the issues arising from the preceding comments. The main issues discussed are that:

- The distinctive issues for people who have been diagnosed younger with Parkinson's disease are not recognised in the service system and as such are 'invisible' in terms of service planning and design.
- The starting point for an appropriate service response for this group is ensuring consistent administration of medication. This must be tackled as part of designing options to solely family or individual-based support arrangements, particularly for out of home living and respite.
- There are no avenues for people diagnosed younger with Parkinson's to explore and plan for their preferred future lifestyle given the stages of the disease progression. It seems this group are very isolated from the service system.
- In common with other progressive neurological conditions, there is a need to build understanding, expertise and pathways between health and disability/community support.
- Younger people with Parkinson's are most likely to be middle aged – not old. This age range is misunderstood or low priority in terms of program reforms or responses.

The conclusion from this study is that there is a sub-population of people younger than 65 years with moderate to high disability support needs. It is very difficult to identify this group as Parkinson's disease tends to be uniformly treated as a condition of older age and people do not appear to be referred to disability and community support agencies and do not know about them. The following issues include possible next steps to further explore, or respond, to these findings.

4.1 Younger people with Parkinson's disease are 'invisible'

Parkinson's disease diagnosed in younger people is not understood. The magnitude of the impact of Parkinson's disease on a person's lifestyle is greater for people diagnosed younger. That is, the range of effects are greater for people diagnosed younger compared with older, as older people tend to be retired, have adult children (an additional source of support), be at a different stage in terms of their lifetime achievements and expectations, and have organised their lifetime finances. Similarly, there is a different effect on younger family members, notably partners, as carers will be caring longer at a time when they may also have additional major work, study and childcare roles. This creates particular needs for information to families, carer support and respite arrangements relevant to this younger age group.

For people diagnosed younger with Parkinson's disease, the support response should therefore mirror the range of lifestyle areas which have been disrupted and aim to maximise life quality for as long as possible. People with young onset Parkinson's disease require a

very different set of supports to cope with different impacts to people who are older at the age of onset. People with no family or informal supports will have difficulty living without assistance, carers may be unable to continue without assistance, and these situations may result in people seeking out of home accommodation. Planning for such supports is ideally gradually explored from diagnosis.

However, there was marked confusion or uncertainty from individuals, family members and various staff during this project about programs or entitlements (such as mobility or carers allowances). It is not well recognised in the service sector that:

- There are younger people (below 65 years) with Parkinson's disease. While it will be 5-10 years before the physical effects of the disease and the medication side effects impinge on daily lifestyle there are important information, counselling and planning roles relevant from diagnosis.
- That Parkinson's disease involves inevitable progression to severe disability, which may not be experienced by older people due to end of life. Younger people will experience the more debilitating later stages 3, 4 and 5 of the condition and this will occur before many people are 65 old.
- Parkinson's disease is not a condition exclusively of older age and is likely to be more aggressive for people who are younger. The service system responses should be different for the different age groups.

Despite the projected numbers, it has been difficult to identify significant numbers of younger people or their carers. Anecdotally, very small numbers of younger people with Parkinson's are presenting – or being accepted - at disability and community support programs.

Exceptions are ACAS and probably Carers' support. The reasons for this are proposed to be some or all of the following, but more research is needed:

- People may be managing daily life well for the first years after their diagnosis. Information and medication are the priorities and these do not require longer term planning.
- There is no single point for all (younger) people with Parkinson's. There are many GPs/neurologists and not all people are linked to Parkinson's Victoria. Not everyone is linked to a neurologist. No one has aggregate data except perhaps ACAS, and this would not cover the wider lifestyle support needs for this group.
- Symptoms, drug side effects and lack of drug 'coverage' for motor impairments are more likely for people older than fifty years. The age group 50-65 years are eligible for disability services but also have a history of access to aged care. It is not clear if younger people with Parkinson's are referred to ACAS, or if they are then referred to disability and community supports.

- Issues for younger and older people with Parkinson's and their carers are not always differentiated so that support groups, focus groups, carer groups are predominantly representing older people.
- Less is known about younger people with Parkinson's as they don't appear to have been distinguished in data collection or studied separately according to life stages.

4.1.1 Possible next steps

- *Develop a distinct profile of symptoms, support needs and issues and data about younger people with Parkinson's disease in Victoria.* Make this profile distinct from issues for older people. Consider:
 - Undertaking ongoing research and needs data analysis specifically for people diagnosed younger.
 - Establishing a contact point for information and advocacy
 - Providing information about this younger population to health, aged care and disability and community support planners and providers.
 - Developing information and referral pathways between health, ACAS and disability/community support. Review the practice arising from the protocol between Disability Services and ACAS for this younger population.

4.2 Resolving the medication disruption

Management of medication is the number one concern of respondents. This consistent experience of disruption of the medication regime and the dire consequences described understandably increase the calls for Parkinson's specific services. The questions remain as to how the Parkinson's-specific information and practice is best introduced and maintained and why it is that residential aged care and health settings are reported to be unable to reliably maintain medication regimes.

What is surprising is that this is the one priority consistently stressed by respondents and carers – medication management to minimise symptoms and deterioration – and it is reportedly not well managed in current respite and health settings. Yet no systemic response has been initiated to overcome such drug medication inconsistency – and this was identified in Fyffe (2002) and is the high priority in the recent Parkinson's Victoria Consumer survey and the current interviews. There are two aspects here – improving systemically inadequate medication management and developing housing and support arrangements with suitable medication management.

4.2.1 Possible next steps

- *Investigate how to improve the reliability of medication administration, perhaps through the training or standards accreditation agencies.*

4.3 The importance of lifestyle planning and support

Younger people with Parkinson's and their family/carers are very isolated from the service system. The reason for this is not totally clear. They are not recognised as a distinct sub-group of people with Parkinson's and so may be 'hidden' within aged care responses. This leaves many people fearing their only option is residential aged care when they can no longer live at home due to a decline in independence or lack of family support. People may be referred to ACAS, neurologists and movement disorder clinics but have not been identified in expected numbers at disability intake, community health or Linkages. The risk of residential aged care following acute hospital episodes also requires further research. It is important to develop a profile of younger people diagnosed with Parkinson's disease, distinct from older people and begin to distinguish between people who are younger and older for community, disability and ageing responses.

The emphasis for service planning (apart from medication and movement disorder responses) seems to have been respite, equipment and care support, but not wider lifestyle planning. The other aspect of support is through support groups which are chosen by some people. The emphasis has been fitting people into service types, rather than lifestyle planning. There was limited lifestyle support reported to assess declining functional ability and adjustment to changed roles, for example, support to remain at work, how long to drive, or changing relationships with a partner. Gradually the spouse/partner is considered the carer and not wife/husband or friend. Age of onset (younger versus older) determines at what point in the life course symptoms have an impact and should influence the nature of the family support needed (for example, older or younger children, retired or working).

People described the critical areas for support as:

- Reliable medication management
- Planned not crisis responses – so that the individual and carer have a sense of control about the future
- Maintenance of social links and personal interests
- Equipment, technology and adaptations as needed
- Regular person /attendant support, including way to respond and support periods of fluctuating abilities arising from unexpected freezing and medication 'on/off'.
- Respite which is enjoyable for the individual and planned to complement the carer's and individual's lifestyle.
- The need for services throughout Victoria and not concentrated in some parts of metropolitan Melbourne.

Many people seek advice, information and treatment for specific symptoms arising and the impact on their lifestyle. There was little description of early information and planning about

personal and family priorities and how this may be affected by the progression of Parkinson's – how can individuals maintain life quality through social relationships, personal interests, maximise independence and share support provision with family, at each stage. There seemed to be a notable lack of planning for the longer term community and disability support needs of the younger onset group, particularly housing and support which are the foundation for daily living arrangements.

4.3.1 Possible next steps

- *Identify and provide or negotiate for the types of support likely to be relevant to the different stages of Parkinson's disease, commencing with diagnosis, information, counselling and future planning; in home and community arrangements for regular and unpredictable support to maintain preferred lifestyles; information and assistance for family members including in their role as carers. Consider:*
 - Establishing an ongoing and proactive case management / coordination role for younger people. Initiate (referral for) lifestyle and needs planning for younger people with Parkinson's disease.
 - Trialling and assisting referrals to disability support services.
 - Undertaking systemic advocacy about the development of relevant and responsive support for younger people with Parkinson's and their families.
 - Trialling small scale options for supported community living arrangements.

4.4 Coordination across health, community and disability support

In common with other progressive conditions (such as multiple sclerosis), responses to the illness (for example, medication, therapy) as well as disability and community support (for example, building and maintaining social relationships, maintaining interests and having something meaningful to do, support for personal care) are all important. Unlike other progressive conditions affecting younger people where progress has occurred with service system coordination and response, the service system - health, aged care, disability and community support do not reportedly have a common or coordinated understanding of the support needs for younger people diagnosed with Parkinson's disease.

It is difficult to make even preliminary generalisations about the service system pathways for this group except to say, there are multiple points of diagnosis, referral is not able to be coordinated through the information role of the Parkinson's Victoria and there is little distinction between pathways which could be developed for younger versus older people with Parkinson's. This finding was not consistent with what younger people with Parkinson's were describing as their aspirations of community living or their likely support requirements. There was a sense of systemic isolation whereby individuals and carers didn't know what was possible. This is regardless of whether supports are actually available due to budget limits, priority of access processes etc.

The findings are restricted by the lack of distinction in many groups responding between the issues for younger and older people with Parkinson's; and the lack of understanding of how many younger people there are requiring disability and community support for housing; and the lack of a concerted advocacy strategy to identify needs for this group. There is no question from this research that for people diagnosed younger with Parkinson's there is little uptake of community and disability support programs and little overall planning for quality of life issues in a preventative or life stage sense. There is no one process or pathway for referral and diagnosis and not everyone has contact with a neurologist. Hence even referral within the health system was variable. It is therefore probably not surprising that referral to disability and community support agencies and exploration of alternative supports to community based housing arrangements have not been explored.

4.4.1 Possible next steps

- *Establish experts in 'navigating the system'* as local resource people. Consider:
 - Monitoring the effects of timely and earlier referrals as a basis for improved life quality, maintenance of supportive community living arrangements, and avoiding early residential aged care admission through acute hospital episodes.
 - Providing capacity for Parkinson's specific training and materials development.

4.5 People aged 50-65 years – misunderstood and a policy challenge

The starting point for this project was that aged care system, and residential aged care in particular, was inappropriate for younger people with Parkinson's disease. The sentiments for this starting point have been well debated in the community in recent years culminating in the COAG agreement about developing options to residential aged care for people younger than fifty years. In Victoria, the 'My future, my choice' initiative arises from this direction nationally. It is recognised that residential aged care is predominantly available for people near the end of life, and most commonly this means people in their eighties. That is, younger people are at a different life stage in terms of family roles and relationships, interests and pass time to older people; and residential aged care is not well placed to provide holistic and longer term quality of life support. People aged between 50 and 65 years are to some extent in a policy or response vacuum whereby the appropriateness of aged care services can be questioned as limiting in focus but this group have not been identified as a high priority for alternative reforms. However, this is the age range when young people diagnosed with Parkinson's are most likely to experience the higher support implications of the condition. None of the younger people interviewed, their carers or many staff believed residential aged care was a suitable or satisfactory location for respite or longer term but there were no other community

living arrangements and supports reportedly available. Residential Aged Care may be suitable for people in the final stages of Parkinson's disease.

This group, however large, who are experiencing high support requirements between 50 and 65 years are, without advocacy, and are caught in a systems low priority area. Effort is currently being directed towards people younger than 50 years at risk or in residential aged care. There is general misunderstanding of the condition that it is both benign and a symptom of early ageing.

While Parkinson's may be more common in older people, it is a chronic illness with associated disabilities, not a pre-condition for getting older. As with all contemporary understandings of disabilities, the nature of peoples' support requirements is a function of their life stage, personal preferences and treatment and disability types. It would seem Parkinson's disease with younger people continues to be viewed narrowly in terms of a health and ageing paradigm. This was the case for the other progressive neurological conditions (notably multiple sclerosis, Huntington's disease, motor neurone disease and the muscular dystrophies). While attention to medical and drug interventions remain a high priority in research in response to people with these other conditions, the supports required to maintain quality of life in community settings have expanded in recent years consistent with the needs of these groups (for example, rapid response to people with Motor Neurone Disease; emphasis on recreations and social programs for young people with Muscular Dystrophy). Given the demands on all parts of the service system, it is important to build understanding and awareness about the needs of this specific sub group.

4.5.1 Possible next steps

- *Establish the systemic capacity to undertake these recommendations, consistent with the systemic advocacy, information and case coordination roles of the other progressive neurological agencies that span health, aged care and disability support service responses.*