

**LIVING WITH YOUNG ONSET  
PARKINSON'S DISEASE**

**The issues and impact of young onset  
Parkinson's disease in Australia**

**The Young Onset Parkinson's Project is a collaboration between the  
'Parkies with a Purpose' support group and Parkinson's Victoria.**

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## **EXECUTIVE SUMMARY**

People with young onset Parkinson's disease have different information, advocacy and community support needs from people diagnosed with Parkinson's in their older years. This has not been recognised in Australia, despite extensive service development for people with other progressive and disabling conditions that develop in young and middle adult years, and unlike the situation for people with young onset Parkinson's disease in USA and UK.

Parkinson's disease is a severely disabling condition for the significant sub-group of the population of people with Parkinson's disease who are diagnosed younger. Unlike many people diagnosed in later life, younger people typically live for decades with the condition and experience the full spectrum of the condition's debilitating physical, cognitive and emotional effects. These effects are occurring when people have very full lives and when people's identities and futures are being shaped by pursuing careers and accumulating assets; forming and maintaining close friendships and partnerships; establishing families and raising children; and engaging in active and social leisure pursuits. This is also the time for laying the foundations for retirement and older age.

For the first time in Australia, people with young onset Parkinson's disease and their family members were asked to identify the issues and impacts arising from living with this condition and to make comment about the availability and appropriateness of current services and supports. Respondents described how young onset Parkinson's disease introduced major disruptions and changes to their personal, family and work lives. People wanted ongoing research to find a cure for Parkinson's disease; accurate technical and peer information about Parkinson's disease from specialists and other people living daily with Parkinson's; and information and coordinated support to live as well as possible despite varied and changing emotional, physical and cognitive effects. Descriptions of anxiety, stress and uncertainty in daily life were frequent. People wanted expert medical response to the disease — diagnosis, symptom management and medication regimes — and nearly all respondents were in contact with neurologists, GPs and Parkinson's associations. Respondents also wanted advice about how to *live* with Parkinson's. Surprisingly few people had tried other professional and community support services such as counselling, employment assistance or financial planning. There was frustration and distress when staff in these various community support or health services did not understand the issues for people living daily with young onset Parkinson's disease.

As the project was initiated by Parkinson's Victoria, the findings are directed in the first instance to the role of Parkinson's associations. There is a need to promote the profile and issues for people with young onset Parkinson's disease so that individuals and their families can easily find information; and professional, health and community support services can develop and respond to how people can live their preferred lifestyle as well as possible. Parkinson's associations are potentially well placed to be the conduit between, on the one hand, specialist medical and diagnostic processes and, on the other hand, access to coordinated support for community living. This includes individual and system-wide information about what is available; development work with community agencies to ensure their relevance to people with young onset Parkinson's; and assistance to people with young onset Parkinson's to network, support each other, lobby and advocate. There is also the opportunity for the associations to develop improved databases and foster new directions for research sensitive to the circumstances of people *living* with young onset Parkinson's.

## **BACKGROUND**

Parkinson's disease is generally thought of as a disease affecting people in older age, when people have ceased working, raised families and planned their retirement. This means information and services that have been developed are concerned with people in their later stages of life and will not be relevant for younger people (Spillare 2007). Young onset Parkinson's disease commences during young and middle adult years. These are the foundation years for forming relationships and rearing children, career development, assets acquisition, active leisure and recreation, and planning for a secure future. Many people find that it is the psychological, emotional and social consequences of living with Parkinson's that have the greatest impact. Common concerns therefore relate to employment, finances, relationships and raising children (Parkinson's Disease Society UK 2009).

People with young onset Parkinson's disease are a significant sub-group of the overall population of people with Parkinson's disease. It is estimated that approximately 18 per cent of the population of people with Parkinson's disease is of working age, which is about 10,000 people Australia-wide (Access Economics 2007). One in twenty people will be aged younger than 40 years at diagnosis (Parkinson's Disease Society UK 2009). It is likely that this is an underestimate of the number of younger people with Parkinson's disease as this diagnosis is often overlooked in this age group (American Parkinson Disease Association 2008).

Unlike people diagnosed older, people with young onset Parkinson's will live with the condition for decades (Ishihara, Cheesbrough, Brayne, and Schrag, 2007); are more likely to experience the full spectrum of the condition's debilitating physical, cognitive and emotional effects (Access Economics 2007); and may develop significant medication side effects arising from the prolonged use of medications (Parkinson's Disease Society UK 2009). About one-quarter to one-third of younger onset people have moderate to high needs now. The remainder will have high needs over time, and for many of this group they will probably still be within the younger age range (Access Economics 2007).

The importance of responding specifically to the issues for people with young onset has been recognised in the UK and USA (e.g. the Michael J Fox Foundation, see Spillare 2007). People's working lives may be extended as a consequence of many individual factors (such as assistance with physical and emotional symptoms) and workplace-related factors (such as changed tasks, adjusted schedules, an easier or different job, or the possibility of extra breaks) (Martikainen, Tiina, Luukkaala and Marttila 2006). However, there is little

research available to assist people to maintain gainful employment as one part of making plans for their future (Shrag and Banks 2006). Understanding the nature of people's support needs arising from living with young onset Parkinson's is critical to ensuring that people have relevant assistance and information to maximise their quality of life. This is the focus for the current project. This information has not been previously collected in Australia.

### ***1.1 Introduction to this project***

This project is the second project investigating issues for people diagnosed younger with Parkinson's disease, auspiced by Parkinson's Victoria and 'Parkies with a Purpose', a Victorian support group of people diagnosed younger with Parkinson's disease. The first project (Fyffe 2007) identified that it was difficult to describe the profile and issues for this younger onset group, who were very isolated from the service system in terms of information, service planning, design and provision. There were no avenues identified for people diagnosed younger with Parkinson's to explore and plan for their preferred future lifestyle given the stages of the disease progression. It was found that people with younger onset Parkinson's disease were not referred to disability and community support agencies and did not know about them. The current project was therefore designed to describe the information and support needs of the younger onset group, specifically to:

Develop a distinct profile of symptoms, support needs, issues and data about younger people with Parkinson's disease in Victoria, and to make this profile distinct from issues for older people.

As the project was initiated by Parkinson's Victoria, the findings are directed in the first instance to the role of Parkinson's associations.

### ***1.2 Method***

The Young Onset Parkinson's Project commenced in early 2009 and was completed in early 2010. The advisory group met every 4–6 weeks over the course of the project.

#### **a. Defining young onset Parkinson's disease**

Several ways of defining 'young onset' were considered. For example, younger than 40 years (American Parkinson Disease Association 2008), anyone of working age (Parkinson's Disease Society UK 2009) or leaving the decision about 'young' with the individual and having no set age (Spillare 2007). For this project, 'diagnosed younger with Parkinson's disease' was defined in terms of working life, thereby distinguishing in Australia between those of typical working age and

those of retirement age. 'Young onset' therefore meant anyone diagnosed with Parkinson's disease younger than 65 years, particularly people diagnosed in their younger and middle adult years. This included people now over 65 years who have lived with Parkinson's disease for many years.

## **b. How the information was gathered**

The Young Onset Parkinson's Project involved three stages:

- Stage 1, Review of Victorian databases. The aim of this stage was to locate data sources that could help to quantify the number of young onset people within the total population of people with Parkinson's disease in Victoria. Given the data is not comprehensively collected at a state or national level, it was planned to analyse some more local databases, such as information available from Parkinson's Victoria, the movement disorder clinics and, perhaps, neurologists.
- Stage 2, Two surveys. There were two surveys, one for individuals with young onset Parkinson's disease (referred to in this report as Group 1) and the second for their family members and friends (Group 2). Both surveys asked similar questions about the person with Parkinson's. The questions asked for comment on whether changes had occurred in nine life areas relevant to people with young onset Parkinson's disease: employment, personal relationships, leisure and recreation activities, finances, ability to live independently, child rearing, changes to living arrangements, emotional effects, and emotional effects on spouse or partner. Respondents were asked to rate, for each of these areas of life, whether there had been changes due to Parkinson's disease, and if so, whether those changes were judged negative, positive, or both positive and negative. For example, Has having Parkinson's disease affected your employment? Indicate either:
  - negative changes, e.g. lost job; early retirement; stress from hiding diagnosis from workmates
  - no changes
  - positive changes, e.g. unexpected consideration and caring from work mates; employment continues and employer is understanding
  - both positive and negative changes e.g. eg not able to work in the same way but employer has modified requirements, or
  - not applicable

There was also the opportunity for descriptive comments.

The surveys were distributed initially in Victoria and then distribution was extended nationally. The Parkinson's associations in each state, the

Parkinson's Victoria website, and support groups advertised and distributed the surveys, electronically or by mail. People could respond anonymously or could elect to provide contact details and therefore be contacted about the subsequent workshops. Of the 123 responses from people diagnosed with Parkinson's disease younger than 65 years (Group 1) approximately two thirds were men and one third were women. There were 89 responses from family members and friends (Group 2). Eighty-one of the Group 2 respondents described themselves as 'spouse or partner' and seven people described themselves as relatives or friends. Nearly all of the respondents in Group 2 were family members, typically women and most of these respondents were wives.

Both groups reported that about 4 in 10 respondents with Parkinson's were younger than 50 years when first diagnosed. This proportion increased to about 6 in 10 with people's estimates of when symptoms first commenced.

The largest subgroups of respondents for both groups lived in Victoria. Most respondents in all states lived in capital cities. These figures reflect the greater advertisement of the surveys in Victoria and the demographic of Australia, where most people live in capital cities. The results presented are based on the total respondent groups only, as state-by-state comparisons were too small and disproportionate to be meaningful.

- Stage 3, Workshops with both groups. There were three workshops, held in November 2009. There was a workshop comprising invited representatives with young onset Parkinson's disease from each state Parkinson's association. There were two representatives each from Queensland, NSW, Western Australia, South Australia and three representatives from Victoria, a total of eleven people. In addition, there were two Victorian-based workshops. Individuals and family members residing in Victoria who had completed the national survey and provided follow-up contact details were invited to these workshops and this invitation was also extended to anyone who had not completed the survey, for example, a spouse, relative or friend. There was a total of 37 people at the Victorian-based workshops, of whom 21 were people with young onset Parkinson's disease and 16 were family members, typically spouses, but including other relatives. The age range of workshop participants with young onset Parkinson's disease was from 25 to 61 years.

### **c. Limits on the findings**

The findings report on some specific issues for individuals with young onset Parkinson's disease and their families and friends. The emphasis was the individual with young onset Parkinson's disease, with more limited exploration of the experience of family members and friends. The survey results present an initial overview of issues; it was not possible to use the information to provide more specific state-by-state information due to the unequal response levels across Australia. There is obvious potential to expand the survey.

There is no information from those diagnosed younger who are now in older age. The results from Fyffe (2007) suggest that, with age, people's priorities move more towards accessible housing and support for daily living. There was no direct comparison with people diagnosed older with Parkinson's, that is, older than 65 years. However it is not unreasonable to assume that issues like employment and child rearing are less relevant to older age groups — but this has not been explicitly researched at this point. It remains possible that the issues facing older people with Parkinson's are being conceptualised too narrowly.

The survey and workshop comments are from people who chose to respond and a percentage agreed to further follow-up. It is not possible to know the extent to which these people's characteristics and comments are representative of those facing younger onset people in general. Respondents included many people who have been recently diagnosed or within, say, the last five years, and many people had a spouse or partner, most frequently a wife. There were few other family members involved, or friends, and few people who did not have a supporting family member or partner. It is possible that these gender and relationship differences skew some of the responses.

There are limitations arising from the nature of the ratings used for the survey questions and the ability therefore to compare different results statistically. It is possible that different people assumed different meanings to the ratings. As one person noted, *When assessing changes, do you mean today, yesterday or overall?* The variability of Parkinson's disease person-by-person and day-by-day makes this particularly pertinent. Subsequent comparisons between questions are based on the magnitude of responses between respondent groups and are suggestive only, with no rigorous statistical basis for data comparison. These trends are supported by the descriptive comments. Similar issues arose across all information sources and for both respondent groups.

## **2. FINDINGS**

This section brings together information from all data sources, under key headings. The data report is available from Parkinson's Victoria.

### ***2.1 Databases***

No database was located in Victoria in which the number of people diagnosed young with Parkinson's, as a subset of a total population of people with Parkinson's disease, could be easily ascertained. Either the appropriate information is not being collected (i.e. age of onset or diagnosis) or there are logistical issues in establishing the appropriate database (current databases are not electronic; there is a lack of coordination among databases etc.). There is also the possibility that diagnosis of Parkinson's disease may be confounded with other neurological conditions due to the frequently extended diagnostic process.

### ***2.2 Living with young onset Parkinson's disease***

#### **a. General issues**

This section contains the findings of what people with young onset Parkinson's and their families say are the issues, organised according to major themes. Within each theme, there are two subsections: trends from the survey data and comments and issues from the surveys and workshops. Written comments from both sources (appearing in italics) are used as examples of the issues.

##### *a. Trends from the surveys*

The vast majority of both groups of people completing the surveys said that having Parkinson's disease meant limitations, changes or disruptions to their lives. These changes typically had a negative aspect, although many people rated changes as encompassing both positive and negative aspects. For example, in regard to personal relationships, some friends were not supportive but others became closer friends.

##### *b. Comments*

Respondents stressed the importance of not simplifying the issues, as everyone has different circumstances. It was felt that there is more variation in the young onset group than the older onset group, as the age range runs from people in their 20s, and perhaps younger, to those in their 60s.

As the circumstances facing young onset people are not well known, many respondents recognised their potential role in speaking up about what is needed.

Some people emphasised the importance of telling other people and the wider community: *I have Parkinson's disease*. Some people found it very difficult to tell others: *I don't always have it in me to explain*.

There was discussion about suitable language. Participants wanted better language about Parkinson's disease to help with explanation to others:

*Parkinson's disease is not illness or a disease. You can't catch it! It's a condition ... a disorder. I'm not sick.*

The term 'carer' was deemed appropriate by some and criticised by others as younger people may be caring for other family members. For example,

*I'm still looking after my children. Who is the carer?*

Some partners also rejected the seemingly automatic application of the term 'carer' to them: *I'm a wife not a carer*.

## **b. Issues at diagnosis**

### *Trends from the surveys*

Around half of the respondents in both Group 1 and Group 2 described the process to reach diagnosis as 'long and difficult', because of the time diagnosis took and the emotional distress that occurred during that waiting time. Just over four in ten respondents described the diagnostic process as easy.

### *Comments*

Many people praised their current general practitioners and neurologists:

*The diagnosis took over 18 months. Once we found a great neurologist, the amount of information and support was very good.*

Several people described the difficulty of getting a diagnosis and feeling that they were educating their general practitioners about the condition. There was frustration with doctors looking at many other potential diagnoses before considering Parkinson's disease because this diagnosis was only associated with older people. People felt the presentation of a younger, fit, healthy and active person doesn't align with professionals' ideas of Parkinson's disease. Examples were given of being treated by various therapists, masseurs etc. for frozen shoulder, bursitis and other conditions. People could 'look back' and realise they had symptoms of Parkinson's well before diagnosis:

*Many minor physical problems disappeared after Parkinson's disease medication.*

Some general practitioners and other medical or hospital staff often didn't have enough information about Parkinson's disease, including medications. Medication regimes were constant topics of conversation, from the difficulty of maintaining the timing of medication (especially in hospital) to the significant side effects. For example,

*Medication can change cognition. What's most important?*

*It took me years to realise some of my symptoms were actually from the medications!*

People wanted a direct link to available information and services, preferably from the neurologist or general practitioner. However, few neurologists and general practitioners were reported to take on that role.

*It's difficult to get accurate information and to find out what is available.*

*All services that were useful I tracked down myself.*

Information is needed for community members, professional groups, individuals and their families:

*Need to increase awareness in general community and specific professional groups, as well as information for people with Parkinson's and family and friends.*

*Want information about Parkinson's disease in the family and genetic implications, such as for children.*

The lack of coordinated services has created a 'double-edged sword' as *people are required to link into services to prove need, but if people don't know about them how do they link in?* It was also noted that not everyone is eligible for existing services even if they did apply, and there are different state-based systems.

### **c. Daily life with Parkinson's**

#### *Trends from the surveys*

Both groups indicated a comparatively greater rate of 'no changes' in the ability to live independently than for other areas of life (greater than one-third but less than one-half). Group 1 respondents indicated more changes that were both positive and negative, while Group 2 respondents had a slightly higher rate of negative changes. Two-thirds of respondents in both groups reported no change to where they were living.

## Comments

There were many, many comments describing physical changes arising from Parkinson's disease. These comments reinforce both the variability and impact of the condition.

*[PD] has seriously affected my ability to sleep and relax.*

*I can't walk as well. I get tired quicker. I ache terribly at times.*

*Restriction on all things — sleep; not able to work; eating only what doesn't affect the tablets; you live with this Parkinson's disease — it's in your way and in your face 24 hours a day.*

*Loss of weight, loss of energy, less vocal strength and clarity of speech, less sexual activity and less flexibility.*

*Lack of strength is noticeable. Now just getting something from the back of a low cupboard is impossible.*

*Loss of independence and ability to get involved in things of interest away from home.*

*Difficulty in multi tasking makes some social/family situations difficult to handle.*

*Difficulty writing makes attendance at meetings/seminars and completing forms difficult.*

*Memory loss is upsetting as we have found that the memory of things pertaining to him directly is good but anything else is questionable.*

People gave examples of daily and varied experiences and frustrations of living with Parkinson's:

*The effects of minor physical problems mean difficulty signing name; using computer mouse (e.g. pressing keys too long, and deleting or multiple strokes); these aren't talked about.*

*Sleeplessness — is it Parkinson's, medication or me?*

*I can't blame Parkinson's for my golf — I've never been very good at golf!!*

*Mental activity changes with Parkinson's: I have difficulty with multi tasking.*

*Packaging, I can't open it!!*

Many activities have become difficult, although the fluctuations in abilities added a further dimension:

*It's hard to plan ahead because we don't know whether it will be a bad 'parkie' day for him.*

*Factors such as temperature, tiredness, diet and regularity of meals, social and work pressure, gross and fine motor skill demands/tasks and mentally complex tasks, either on their own or in any mix, then superimposed on Parkinson's, produce an array of performance-limiting outcomes.*

*My partner changes many times a day from being very capable, via slowness and frustration (this extends to anger when under pressure) to total inability — emotional, intellectual, verbal and/or physical.*

#### **d. Getting on with life**

There were no specific survey questions about this theme.

##### *Comments*

Comments from people with young onset Parkinson's emphasised how much they valued the importance of staying active and participating in the community. After the uncertainty and stress of diagnosis, many people described *just wanting to get on with life*. People wanted the type of information that was often not provided by neurologists, such as the importance of knowing at diagnosis: *It will be all right; I will still be able to contribute*. They wanted to know how to live well with Parkinson's:

*Neurologists don't teach people about living with Parkinson's disease other than taking medications.*

Some people didn't want to have anything to do with other people with (young onset) Parkinson's but everyone wanted information about how to live as well as possible and how to understand the lived experience of Parkinson's.

Planning for the future is very important for this group. Many people are travelling now *and not waiting 10 years into the future*. The importance of being able to do something *meaningful and purposeful* was seen as part of self-acceptance for many. There were frequent examples of people changing businesses, retiring and pursuing a much-loved hobby, or becoming volunteers. People volunteering with Parkinson's associations had often found that new public-speaking role very satisfying. People want to live as well as possible for as long as possible. While expectations of life are changing, people expressed the importance of *getting the balance of life right*. Many people had worked out *how to design life around when you are at your best. Now I work in the morning when I am at my best*.

Some comments emphasised living as well as possible before *we are at the point where Parkinson's is running my life*. There was much mention of self-acceptance, *but how to do this?* There were different ways described to respond to a changed sense of future. Some people had difficulty dealing with what has actually happened. Some were optimistic about the future because of research. Some exhibited thoughtful questioning about what direction life can take. Some felt confident about the new directions they had taken on. There was a strong sense

from some of wanting to help others with Parkinson's. Many comments described how people's plans for the future had changed, including specific plans now being deemed no longer possible, often related to travel and retirement:

*Many things planned for retirement either are not possible or require much planning.*

*The main problem with Parkinson's is that it robs people of a purpose in life.*

Some people have re-appraised their lives and for some this means new directions. For example,

*I've re-evaluated priorities—I have a sense of urgency, i.e. can't waste a minute.*

*Parkinson's came at a time in my life where my children were just leaving school, the house was paid off, so ceasing employment was an option. It has made me re-assess life, and I have travelled extensively since being diagnosed; something I might not have done otherwise.*

*I appreciate what a fabulous life I have.*

*I've taken up writing to maintain hand flexibility — and have had a book published.*

## **e. Emotional wellbeing and mental health**

### *Trends from the surveys*

From the survey, about half of the Group 1 respondents reported a combination of positive and negative emotional changes ('how you feel about yourself') and just fewer than half reported negative changes only. About half of both groups estimated that their spouses experienced positive and negative emotional changes, and about one-quarter of both groups suggested negative changes only. With regard to emotional effects on the person with Parkinson's disease, more than nine out of ten people in both groups reported changes and the minority of these were positive alone. Group 1 respondents were more likely to report positive changes alone than were Group 2, although this was only a small number of the total respondents. How respondents felt about themselves was the area with the greatest positive and negative changes, being about half of both groups.

## Comments

There were many comments about the emotional effects of Parkinson's disease and people's self-image and identity.

*I have become more determined than ever before (my wife would say bloody minded) to do things around the house by way of maintenance and projects.*

*I have become a lot more assertive as to how I should manage my time and whom I should spend time with. I have deliberately avoided situations or people where I am likely to feel stresses and exasperate the Parkinson's condition.*

*I would like to know more about coping with anxiety and how to calm my nerves when in company with others (get very nervous at times).*

Anxiety, stress and reduced self-confidence accompanied changes in abilities:

*Loss of confidence, rather not meet new people, go to new places.*

*He doesn't cope with new situations or changes in his routine.*

*Frustration would be the major factor — not being able to do things he once could.*

*Parkinson's has affected my husband more emotionally than physically.*

*His confidence has been shattered.*

*Not being able to fulfill lifelong dreams ... having to modify some passions in life. This also removes the social network surrounding this pastime and has impacted on friendship groupings, self-esteem etc.*

*He has retired at 50. He has never 'not worked' and I think will find it hard to adjust to being on the pension.*

Many people described anxiety about the future and were uncertain, even fearful, of the years ahead.

In addition to the physical or behavioural side effects from Parkinson's medication, some people noted other changes and illnesses that affected the person with Parkinson's. This could add to an individual's moodiness and depression and lead to the question 'Is this Parkinson's or not?'. For example,

*He becomes frustrated more often, tired a lot these recent days. I think he feels sad not to feel like the strong male he was but not sure how much this has to do with Parkinson's disease or just age related.*

*Is this Parkinson's, or me, or something else, like just getting older?*

## **f. Employment**

### *Trends from the surveys*

Nearly half of both groups rated changes to employment as exclusively negative. Just over one-quarter of Group 1 respondents rated their experience as both 'positive and negative', such as early retirement and new roles (e.g. as a volunteer), with fewer than one person in ten reporting exclusively positive changes, such as a long-desired career change. Early retirement was often noted as a negative change. Group 2 respondents reported more instances of 'no changes' to employment than Group 1. Group 2 respondents were less likely to report changes to employment as 'positive and negative' than Group 1 respondents.

### *Comments*

People with Parkinson's described being in the asset-gathering stage of life and are concerned when this is disrupted through being unable to work as planned. Many people described changes to their employment circumstances since Parkinson's was diagnosed. Changes to employment have obvious implications for current and longer-term finances and is different from the situation applying to older people who may have already had the opportunity to prepare for cessation of a full-time income. There were marked variations in people's circumstances. People with well-established careers or those just starting out and studying described the different disruptions caused by Parkinson's disease. Some people were less well insured or couldn't continue to do physical work. Some people had income insurance. What decisions people made about retirement, retraining or redesign of their work, or moving to volunteer roles, seemed to depend on individual preferences about working or not, and many other factors, including:

- years till typical retirement age
- the employment status or potential of a partner/spouse
- the nature of the work and the workplace
- employment arrangements (e.g. self-employed, government, private)
- requirements of the job, including stress and physical aspects
- flexibility of the employer
- the transferability of someone's skills to other settings or roles
- the nature, progress and impact of Parkinson's symptoms.

There was also concern that younger people with Parkinson's are:

*falling through the gaps — they may have to retire from their current employment because it is too demanding, but they struggle to get a*

*disability payout from superannuation because they may still be capable of working part-time in easier jobs.*

Some people could adjust their daily lives to accommodate changes caused by Parkinson's disease:

*My 'person with Parkinson's' deterioration is quite slow and since he has always been self-employed he can continue at his own pace.*

It was felt that employment services aren't usually helpful because:

*They don't understand Parkinson's disease and how it makes work difficult. Many Parkinson's disease symptoms cannot be seen and so employers fail to see why it is a problem. They (employment services) tend to specialise in people who have a broken back, or no leg ... they don't know how to help people with Parkinson's.*

However, there is a potential role for employment services:

*More help should be offered to Parkinson's people to find suitable employment, e.g. gardening, librarianship, new training and assistance.*

Others described specific loss of vocational or social activities linked to work:

*Loss of work-related friends.*

*I can't carry out my normal functions, like typing, limiting my professional abilities.*

Partners' employment was also affected. Some partners increased their caring role, and reduced employment, with accompanying fears for the future:

*Husband took early retirement to become full-time carer.*

*I'm concerned about my loss of ability to go to work and that eventually I will be housebound to look after him, with no assistance.*

*Additional caring responsibilities affected ability to hold down a high-responsibility job with irregular hours, such that early retirement was taken to become a full-time carer.*

Other partners have increased employment to balance financial changes:

*I've had to work more since he had to leave his job and that makes it difficult to get to regular events.*

## **g. Finances and assets**

### *Trends from the surveys*

As with employment, about 50 per cent of both groups reported negative changes to their financial position now and into the future. Group 2 reported fewer changes (i.e. more reported 'no changes') than Group 1.

### *Comments*

Financial circumstances are intertwined with employment options. Relevant personal financial circumstances (such as current salary, assets, home ownership and accumulated wealth, insurances, superannuation, and eligibility for government subsidy and benefits) determine financial security for now and the future regarding the needs of the family, especially regarding dependent children and the costs of Parkinson's medications and treatments. People's financial circumstances and age determined eligibility for Centrelink payments and therefore subsidy for costs of drugs, visiting medical practitioners and various therapeutic treatments (such as massage and acupuncture).

The effect of disrupted employment has significant financial implications for the family breadwinner, typically a man:

*My opportunities for employment have diminished, though not from lack of trying, and my financial position is very tenuous. Try running a household, paying off a loan, providing for a young family and having some semblance of life on a pension — it is virtually impossible.*

Financial difficulties were also highlighted in relation to the costs of Parkinson's treatments and medications, and the lack of subsidy solely because people were younger. There were other examples where the rigid age boundaries in the service system were believed to disadvantage and discriminate against younger people with Parkinson's disease:

*It's not possible to reverse mortgage the house if you are younger than 60 years.*

Participants reported difficulty in attempting financial planning early, that is, after diagnosis but while still working. Participants felt this was because younger people present *looking fit and healthy* and financial planning professionals are reluctant to give specific advice, or to commit to advice:

*This is probably because they don't know a lot about Parkinson's.*

There were specific problems for some with Centrelink regarding income- and assets-tested items. People provided examples of staff *who don't believe the Parkinson's disease diagnosis*, because of its association with older age groups.

## **h. Recreation, leisure and socialising**

### *Trends from the surveys*

Almost half of Group 1 respondents suggested both positive and negative changes to recreation and leisure. A further third noted only negative changes. Nearly half of Group 2 noted negative changes in recreation and leisure, a significant impact. Group 2 respondents were twice as likely as Group 1 to report 'no changes'.

### *Comments*

Some people have found new roles and social networks because of Parkinson's disease:

*[Having Parkinson's] has also widened my network of friends; I have met many interesting people both local and overseas with the common ailment, whom I most likely would never have met.*

Conversely, others described changes to social relationships and leisure activities:

*Less time in the garden; does not entertain like we used to.*

*Time consumption on health-related activities, which could be better spent on other leisure activities — this causes resentment.*

*Very slow in everything I do, this can be frustrating at times.*

*Find keeping conversations going for too long is tiring.*

## **i. Relationships and family life**

### *Trends from the surveys*

The pattern of change to personal relationships with friends and family differed from the ratings about other life areas. Almost one in five in Group 1 reported no changes to personal relationships; similar numbers reported negative changes and one in four people suggested positive changes. The remainder described a mix of changes. There is a trend for Group 2 respondents to be more likely to report no changes to personal relationships than Group 1.

The pattern of responses in relation to the effect on child rearing also differed between the two groups. Group 1 respondents were more likely to identify both 'positive and negative' changes in child rearing, whereas Group 2 respondents (mainly wives) were more likely to note positive only changes. For nearly two-thirds of both groups reports were of 'no change' or 'not applicable', suggesting

no children, no young children or that the circumstances with children had not varied.

### *Comments*

Relationships, friendships and social life are important for younger people. Several people talked about wanting friends, the desire to find a life partner and how Parkinson's disease affects this. There were dilemmas about how to tell people and how to work through it. Partners were a potential source of strength but many relationships struggle or break down.

Child rearing was not an area of significant change for many in the surveys, but discussion indicated it was a high priority for a few people. In particular women wanted to know if they could have children and reported that it is difficult to get professional advice. Little information was reportedly available about Parkinson's disease drugs, pregnancy and breast-feeding. Participants had examples of pregnancy with and without Parkinson's medication. There was concern about passing on Parkinson's disease genes to children. One woman recounted her experiences of the career/home balance and young onset Parkinson's disease:

*I'm not working as hard now but have more time with kids.*

It was felt a lot would be gained by women pooling their decisions and experiences regarding pregnancy and child rearing as so little is available. While discussions about having and raising children were led by women they were of interest to those men planning to have children too.

Family and friends want to help and be supportive but they aren't confident in how to do this. They want to know what to do — do they try and slow the person down, do they try and encourage them more to participate? Parkinson's has contributed to multi faceted changes in partner relationships that were described as both positive and negative. Several comments describe the impact on the partner of changing roles and fears for the future. For example,

*I feel I have to shield him a lot more and work situations out in advance so we can both cope.*

*I am now more a carer than a wife.*

*We have been affected less by Parkinson's disease than could be expected so far. Also I've always carried a lot of responsibility, e.g. finances, even before Parkinson's, so this hasn't changed much either. But I know it will get harder in the future.'*

*[Having Parkinson's] has affected my relationship with wife and others.*

Several partners' responses noted their own health conditions, which needed assistance as well:

*I have a few medical issues and he has to assist me at times, which I imagine would be hard for him given his Parkinson's disease.*

Significant reactions also extended to other family members:

*The biggest effect has been his family's reaction. Their reaction has been and still is difficult to live with.*

*Cannot keep up with the grandchildren.*

*I think the most worrying/difficult aspect of Parkinson's disease for my partner is feeling/believing that he won't be around to guide our young children.*

## **j. Different perceptions between individuals and partners**

From the surveys, partners did not necessarily describe changes the same way as their partner with Parkinson's. Group 1 respondents reported the most changes (i.e. fewest 'no changes') for how they felt about themselves, employment, recreation and leisure, and how family members were feeling. There were similar response trends from Group 2, with major changes arising from Parkinson's rated from both groups; however Group 2 respondents were more likely to report 'no changes' in employment and recreation and leisure than Group 1 respondents. For both groups, just fewer than 50 per cent of people reported negative changes in relation to financial position, employment and feelings about themselves.

The biggest differences between the ratings of the two groups occurred in relation to employment and how family members feel (where for both these life areas Group 1 respondents reported twice as many changes as identified by Group 2); and child rearing (where Group 2 respondents reported more positive changes, although the numbers of people responding this way are low).

There were different perceptions between the respondent groups in relation to changes to child rearing, employment, recreation and leisure. Differences between men and women's interests and priorities may explain the different trends. It may be that in relation to employment and financial trends, men with Parkinson's disease are more likely to be concerned with these areas whereas, in relation to child rearing, perhaps female family members saw the person with Parkinson's spending more time with the children and thought this to be a good thing.

## **2.3 About available services**

### **a. Trends from the surveys**

Participants were asked what services and supports would be helpful. Wanting a cure for Parkinson's disease was noted frequently. The vast majority of people (more than 90%) had been in contact with a medical neurologist, GP and Parkinson's associations. About half the respondents had used therapists and support groups. For those services related to key life areas where significant changes were identified from the survey, such as employment, recreation and leisure, financial planning, further education or counselling, fewer than one-third of people reported contact with these services and, while the numbers are small, there were notable percentages of people reporting these services as 'unhelpful'. For instance, 20.5 per cent of people with Parkinson's indicated that they had been in contact with employment assistance services, and of these people, 40 per cent rated the service as unhelpful. Of the 26.1 per cent of family members reporting using financial services, just over one-third (34.8%) rated the service as unhelpful.

The following comments describe what people want and their experiences with existing services.

### **b. Younger people want to be involved**

There were many comments from respondents offering to be involved, be active and contribute, such as,

*[We need] a 'newly diagnosed' pack, containing a gentle introduction into the world of Parkinson's disease services, supports and practical info. I'd be happy to write it!*

There were discussions about the importance of a national approach to young onset Parkinson's disease, involving the perspectives of individuals as well as family members and friends. This approach would strive for national consistency, would not be in competition with states and territories, and would still be encouraging local creativity while reducing duplicated effort. That is, achieving more than can be achieved with current arrangements, but not replacing what is happening at present. How a national network could be organised is still being discussed.

### **c. Finding what is available**

Overall there is not a consistent picture. Some people described good support — sufficient and timely:

*My experience from my first appointment with my neurologist to my meeting the Parkinson's Association has been excellent. The quality and accessibility of information has been exceptional.*

Others described lack of information from professionals, isolation and service shortfalls, particularly in rural and regional areas:

*Our local health service runs all sorts of programs for all sorts of health problems. When I asked them if they ran a program for Parkinson's they said they had no idea in regards to Parkinson's and no plans.*

Many people had difficulty finding what is available and wanted to know about services available generally:

*There needs to be a comprehensive list of all services available, instead of just finding out through other people with disabilities.*

People wanted services to be coordinated and available in rural, regional and metropolitan areas. People in rural and regional areas mentioned the lack of services, and all participants noted the lack of services coordination.

*Suggest regular case management is required — needs seem very individual.*

#### *Appropriateness of what is available*

For many people there have been positive experiences with services and supports:

*My experience from my first appointment with my neurologist to my meeting the Parkinson's Association has been excellent. The quality and accessibility of information has been exceptional.*

There was strong support for the work of Parkinson's associations and their linking role. Many comments praised existing staff and noted they did not have enough time to respond to all demands directed to them. This meant that at times people had found it difficult to locate Parkinson's associations. State-by-state differences in terms of service availability and access were raised.

There were suggestions about how to improve services for people with young onset Parkinson's:

*The associations need to be more proactive with young onset. They need to get young PDers out of home and moving. These people are often without funds or living with very little funds because they haven't worked long enough to accumulate money. They may want to do things and talk about it but it doesn't happen. Someone needs to help them to achieve.*

People without close family are particularly isolated, and will have support needs arising from living alone:

*I live on my own and I do not have a spouse. I would like to work and remain independent for as long as possible. One of my biggest problems is coping with gardens and household maintenance (I cannot do a lot of the things I used to do). Support in these areas would be a great relief, i.e. some sort of tax relief to enable me to hire people to help. This would take a lot of pressure away and allow me to enjoy some quality of life while I still can.*

Many respondents indicated they are not using existing support services because services are deficient in their understanding of young onset Parkinson's. It was noted that people might not use services if they had to identify as being disabled.

#### **d. How and what information is conveyed**

People wanted accurate and up-to-date technical and research information about the issues for people with young onset Parkinson's, as distinguished from older onset circumstances. Coordination of existing information and services locally, nationally and globally was argued for:

*Want coordination across disciplines in order to cope with conditions seemingly not related to Parkinson's.*

*From an information and research point of view I think there is a need for a worldwide coordinated approach. When I'm looking for information and latest research I go to the UK and USA sites.*

Various allied health people were seen as important, including physiotherapists, speech therapists, psychologists, and dieticians. Close contact with a pharmacist can be helpful.

There were also requests for personal stories about daily life, in addition to factual information:

*Education through personal stories — when I was diagnosed I could not relate to any of the information available as it was targeted at 'elderly' people. All I wanted to hear about was someone my age and how they live with Parkinson's.*

While many neurologists were described as very helpful, how some neurologists conveyed information was targeted for improvement:

*We're out of the surgery with a script before we have a chance to ask any questions and with no information. Neurologists should be better prepared to offer support at this point. A brochure with people to contact would have helped.*

There need to be ways to be in contact with people who are isolated, such as people whose first language isn't English. This discussion also extended to information dissemination through a national website using video and audio materials.

There was a request for better information in the general community, to specific staff groups (in particular, health staff) and to people with Parkinson's disease and their families, and that this information, at least in part, be available in GP and neurologist surgeries. There were many suggestions, especially about better information for various specialist and health staff, better services coordination, a single access point for information for people with Parkinson's, and inadequacy of services: *Seems information is available but you have to go searching for it.*

There are implications for how people are treated in daily life because Parkinson's disease is not well understood in the general community:

*When you have a stimulator, the advice from Medtronic is to avoid the magnetic fields associated with shop theft devices. This is very difficult with the current design of many shops, especially many checkouts.*

*My right to have and use a parking permit for people with a disability has always been questioned by those who don't know me. Just because I am not in a wheelchair ... I am constantly made to feel outcast by members of the wider community simply because I may sway or show signs of involuntary movements or that I may struggle to walk ... they believe I am either on drugs, drunk or crazy.*

## **e. Information at diagnosis and beyond**

There were varied information requirements for people newly diagnosed. Some wanted a lot, others little. Planning for the future was important although comments reflected how people respond differently, either wanting information now, or only at a certain point:

*It is still relatively early days for my husband and he has only just retired because he can no longer do the heavy workload. He does not need, or want, any outside assistance at this stage. I guess this will change in the future.*

*At the point of diagnosis all of these services need to be discussed and referred to. The neurologist did not make any suggestions, and neither did the GP.*

*We plan on doing more travel and although we know everyone is different we thought there may be more indications (i.e. averages) on how many years it would be before adventure travel (i.e. lots of walking, riding, kayaking, scuba diving etc.) would be impossible.*

*A lot depends on the attitude of the person with Parkinson.*

The possibility of a person to contact when first diagnosed was frequently suggested, such as a mentor or case manager:

*Want the provision of a 'mentor' program to act as a personal guide through the process of diagnosis to 'enlightenment'.*

*Want a person to talk with you 1 to 1 to indicate the type of services that could be useful to the individuals, and where to contact them.*

Also people wanted information relevant to their life stage and time since diagnosis, with expanded discussion of issues around life stages, not necessarily by age, for example, single or in a relationship, children or no children, and employed or not. This would be in addition to attention to different aspects of Parkinson's: newly diagnosed, planning the future, support to family members.

*Make sure information is given to Parkinson's people about various activities and hobbies that will stimulate their creativity and purpose in life.*

## **f. Responding to the emotional effects**

Emotional reaction to having Parkinson's for the individual and for family members was described, including the occurrence of depression and a lack of counselling:

*It takes a long time to make sense of being diagnosed with Parkinson's disease — both the patient and the family. As the disease progresses and you become more aware of the impact and the future you face, you have to*

*deal with it over and over again and come to terms with things all over again.*

*I feel counselling should be standard practice in the treatment of Parkinson's, particularly for those younger patients as they have so much of their life ahead of them and so much of their future is affected by the illness. A sense of loss and grief is common but doesn't seem to be addressed; nor is depression.*

*Treatment for depression should be standard practice — it rarely gets talked about.*

GPs and neurologists were challenged for discussing only medication and physical impairment, implying an expectation that these professionals could have a wider role in regard too emotional issues:

*I don't feel as a couple or individually we have been supported by the medical profession. My partner sees his specialist and is given medication but, I feel, little else. This isn't support.*

*Need help dealing with the cognitive side of Parkinson's; my specialist focuses on physical symptoms, not emotional or cognitive.*

Participants wanted varied professional support with an emphasis on an ongoing relationship with professional staff — *people who will help, learn more as needed, and can be contacted*. For example, psychologists specialising in chronic illness — not only at time of diagnosis but all the time, especially regarding depression, stress, emotional responses, sense of self.

### **g. Hearing from someone also living with Parkinson's**

People wanted to have someone with young onset Parkinson's to contact, either face-to-face or in cyber space, especially in the first year or so after diagnosis:

*It would be great to have the assurance of someone who has been there and done that ... And most importantly can help pinpoint a direction to turn to.*

*I want to know from a buddy: what are your experiences? How do you cope?*

This person was variously called a buddy, mentor or ambassador. This person would be knowledgeable and available, perhaps someone who had been diagnosed for a longer time period. Family and friends also wanted contact with others:

*Sometimes I could just do with a friend to talk it all through with, who understands what it's like to live with Parkinson's and can help me keep going when it is difficult.*

There were examples described of informal networks. It was recognised that formalising such arrangements would require guidelines and moderation to ensure accurate information. It would be important to distinguish between personal and technical information.

## **h. The role of support groups**

Different support groups are wanted for people with young onset. While some people indicated that their local support group was a source of assistance even when the majority of people were much older, support groups as currently structured were not generally felt to be useful and many younger people rarely attended regularly, if at all. There were several aspects that need to be varied. In the first instance many younger people are distressed by meeting older people who are much more disabled:

*Sometimes we want to meet and forget we have Parkinson's.  
Support groups are a possibility but not with older people. I like the idea of discussing issues for younger people — I want real-life experiences, stories, how people deal with day-to-day issues.*

Further, younger people are often busy with work, family and social life:

*Monthly meetings are too often and only held during the working day.*

There were strong views about the need for the membership, timing and format of support groups to be oriented to young people:

*I attended the local Parkinson group and found no other young people. Most were elderly, just stared and were wrapped up in their own or partner's problems. My son also felt isolated and decided not to go again.*

*Regular meetings for young Parkinson's sufferers would be good, with speakers.*

*The Parkinson's Support group is obviously aimed at people who are unable to work and apart from the inconvenient timing of the meeting, we found it rather depressing!!!*

There were several examples of dynamic networks and support groups for younger people.

There were consistent comments about being pleased to be informed and contacted as part of the project, although many people chose to remain anonymous.

### **3. DISCUSSION AND CONCLUSIONS**

#### ***3.1 Diagnosed younger is different***

For people in this study, young onset Parkinson's disease has shaped their adult years, contrary to their expectations, and well before old age. In common with people diagnosed older there was the desire for accurate information about Parkinson's disease progression, symptoms and medication, including side effects. However, living with Parkinson's is different for younger people. Younger people are diagnosed when they are fit, healthy and active — when life revolves around the importance of work and career development, family life and vigorous recreation and leisure pursuits. Diagnosis was traumatic, unexpected and difficult for many and the emotional repercussions for the individual and their families were often substantial from that time. Parkinson's disease from a younger age introduced decades of uncertainty and anxiety about an unknowable future. This is very different from the experience of living with Parkinson's disease when it is diagnosed in older adulthood.

The young onset group was not uniform. The issues for people diagnosed in their 20s and 30s are very different from those people in their 40s and 50s. There was evidence for enormous variability in people's experience of Parkinson's disease as well as their personal circumstances before and after diagnosis. There was some indication that issues vary in importance and nature between men and women. If people have partners, or want partners, there are also implications in terms of forming and maintaining relationships, having children and role changes for the individuals and close family. For some, personal relationships strengthened, while others struggled. These results highlight that it is important not to simplify all 'young onset' issues in the same way.

### **3.2 The goal is to live as well as possible**

For most people Parkinson's disease has meant unplanned changes to the pattern, direction and expectations of life for the person diagnosed and their family. Typically these changes have not been judged as welcome. There was evidence from some that their personal supportive relationships were strengthened since diagnosis, although this was far from universal. People diagnosed younger with Parkinson's disease want to know how to live their preferred lifestyle as well as possible, for as long as possible, as well as wanting research into a cure. However, even the promise of a cure added to feelings of hopelessness for some, as well as providing hope.

*I really try my best to stay cheerful on top but underneath I deeply resent having this disease, it is something one can never get away from and I can hardly wait for a cure in my lifetime of which I am sure!*

People expressed the desire to continue to live meaningful lives, to contribute, and to have a sense of purpose. Employment for many people in this young and middle age group is an important contributor to people's sense of themselves, and is a source of personal satisfaction, let alone financial security. For some people hobbies, travel, socialising and adventure pastimes were their passions in life that were disrupted by Parkinson's disease. Without purpose in life there were significant implications for the emotional wellbeing and mental health of the person diagnosed and other family members, most frequently described as depression, loss of confidence and heightened anxiety.

While responses from individuals and family and friends (typically spouses) were frequently similar, there were some suggestions of differences. Individuals seemed to be experiencing greater changes in relation to feelings about themselves, and their assessment of the disruptions to their employment, recreation and leisure than was perceived by spouses on their behalf. That is, some individuals experienced the changes from Parkinson's disease more keenly than others may have appreciated. Family members reported more negative changes than people with Parkinson's in relation to the ability to live independently (such as ability to drive; or requirements for more personal assistance from others). This may be a function of the supportive and adaptive role of family and friends, perhaps not recognised or admitted by the individual. It may also reflect overcompensation by family to the changes being experienced by the individual.

### **3.3 New services are needed**

Most people did acknowledge the assistance provided by neurologists, GPs and Parkinson's associations during diagnosis, in relation to medication and

information more generally about Parkinson's disease. However, despite all of the complexities in relation to employment, retirement and financial status, including changes reported in employment status by family members, few people mentioned discussion with their employers, financial advisers and, to an even lesser extent, employment agencies. When this did occur it was rarely judged adequate. Unlike the community supports available to other people of working age with disabling conditions, there was little mention of assistance with maintaining vocational or interest areas along with any adjustments arising from the impact of Parkinson's disease. Some people had single handedly redesigned their work or hobby. Other people wanted assistance and looked to other Parkinson's peoples for personal stories for motivation, ideas and accounts of how others tackle the day-to-day challenges of living with Parkinson's disease: of queues in banks with nowhere to sit; the dexterity required for computer work; or the difficulty of opening a purse quickly to get change. Others described simply withdrawing and becoming distressed.

While most of the respondents were in contact with GPs and neurologists, the medical system did not reliably serve as a conduit to what else is available, although perhaps this is not their role. Parkinson's associations have the potential and willingness to fulfil the role of information provision, including education for various professionals and GPs, but are only just beginning to provide information tailored to younger people and to advocate on their behalf. The Parkinson's associations are also limited by their available resources. It is not surprising therefore that people with young onset Parkinson's are not well known in the wider service system and that databases are inadequate.

Advice and guidance about just what is possible is difficult to come by. There were many similar experiences reported about encounters with the service system. Services relevant to younger and middle aged adult life stages either do not exist or are not informed about young onset Parkinson's disease. The emphasis within Parkinson's networks is on older people and responses to physical symptoms. But this is not the full picture of younger people's lives and expectations, or their families, for the coming decades. Limited assistance with maintaining emotional wellbeing was reported, for individuals or couples, either through professional counselling, or peer support through groups, networks, conferences or mentoring.

The project was an opportunity to bring people in similar circumstances together through meetings and information exchange. This was very important to project participants, many of whom had rejected traditional support groups because members were older and in different circumstances, including more advanced

stages of Parkinson's disease. Participants wanted more and varied opportunities to talk with people in similar life stages. Support groups are not the answer for everyone, and certainly not during weekdays when many younger people are busy with family life, work and other pastimes.

Parkinson's associations are beginning to respond and distinguish their activities for the younger onset group relevant to living with Parkinson's during these stages of life. However, more is needed. What is the best advice about personal finances and when to retire, redesign employment or retrain? Who can counsel about forming and maintaining relationships, about self-confidence, about changing self-image or anxiety and depression, particularly when individuals may be feeling such changes more keenly than close family and friends realise? Who can advise regarding conception, pregnancy, and child rearing? Who makes sure that agencies and professionals have the right information about Parkinson's disease? How can living well with Parkinson's disease be considered in all that happens in people's lives or that of other family members?

While there were many people saying *it's early days, or we haven't had to call on services so far, and maybe in the future*, the same people had also completed the survey describing significant effects of Parkinson's on their lives. This again suggests that the services available are not the right ones. People don't want what is currently available, such as respite and out-of-home support. These are not the supports that young onset people with Parkinson's and their families are looking for. There was less apparent disruption reported by both respondent groups in daily living and where people lived than in employment, finance and recreation and leisure.

### **3.4 Conclusions**

People with young onset Parkinson's and their families reported that they are given little information about how to *live* with Parkinson's disease, nor are they put in touch with other young onset Parkinson's people. They are given information about the disease itself — diagnosis, symptom management, medication etc. — but that's only part of what they are seeking. Many individuals are actively seeking information and are keen to be involved to set up relevant networks, peer support systems and information exchanges. They want high-quality research information about medication and treatment, but also about finances, investment, working productively, maintaining active lifestyles, forming relationships, having children and more. They want information about living with Parkinson's disease to be easily available in different ways — written, face-to-face and electronic — and coordinated across Australia; that is, the best technical specialist information globally expanded with local personal stories and tips for

daily living. It seems opportunities for networking and some of the specialist information relevant to the key life areas investigated are yet to be developed. The findings from this project provide a starting point for further research about the key life areas explored and the different perceptions of individuals with Parkinson's and their family members.

Parkinson's associations are well placed to expand their information and coordination and service development roles, as well as fostering networks development, information exchange and peer support opportunities. There is also the opportunity for the associations to develop improved databases and new directions for research sensitive to the circumstances of people *living* with young onset Parkinson's.

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