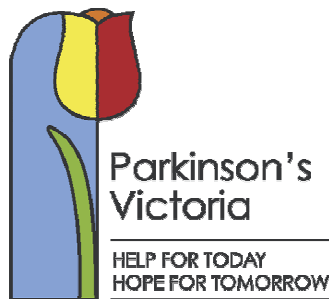


## **“Respite without the Tears”**

### **A Report into the experience of Carers of People living with Parkinson’s, and Respite.**



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## **Respite without the Tears – Final Report**

### **Background**

Parkinson's is a progressive, degenerative, neurological condition which involves a disturbance in the coordination of movement. No two people with Parkinson's are the same, or will experience a similar journey in terms of symptom progression or experiences.

Up to 80,000 people in Australia are currently living with a diagnosis of Parkinson's, with 25 people a day newly diagnosed, and an expected growth in the prevalence by 15% in the next 5 years (Access Economics, 2007). The reach of Parkinson's is felt far beyond that of the person diagnosed, but has a huge impact on the carer, family, community and service system. The condition is life-long and there is no cure available.

People living with Parkinson's (PLWP) rely on medication to try and control symptoms, however, over time the medication becomes less predictable in its effect, making people prone to motor fluctuations and episodes of freezing, where they are completely unable to move. People with Parkinson's are reliant on a strict regime of medication (which is sometimes up to hourly), physical therapy and support from carers. Parkinson's is generally perceived as an older person's condition, however it affects people across the life span.

Access Economics (2007) described Parkinson's as "the second most common neurological condition in Australia [which] remains one of the least understood in terms of its cause. There is a lack of awareness in the health and general community of the challenges and needs of those suffering from this complex and disabling condition, as well as community stigma and constraints in the delivery of health and social support services."

The experience of support agencies, Parkinson's Victoria and Carers Victoria has been that carers of people with Parkinson's have found it difficult to access timely, appropriate respite services for their loved one – to give them a break from their caring role, with confidence that their loved ones needs would not be neglected. In particular, when respite had been accessed, the carers typically have a negative experience which led to deterioration in the health of the care recipient and reluctance for the carer to engage support in again. Fyffe (2007) supports this in her report, stating that carers of people with Parkinson's "coped until they can't" and that there was a very small uptake of support services and difficulty accessing the system in general.

Parkinson's Victoria and Carers Victoria then decided that they would hold forums to discuss the concerns of carers in more depth. This report records the experience of 26 carers of people with Parkinson's (and Progressive Supranuclear Palsy) into their current experience of respite and possible solutions.

### **The role of the carer**

Strong cultural values around family caring – such as 'caring is just what you do for a family member' – tend to render the carer invisible. Health professionals and service providers more often focus on the 'patient' or 'client', which means that the carer is not included in care planning or in discussions about their own health and wellbeing.

There is now a substantial body of research that underscores the detrimental health impacts of providing care. More than 60 percent of carers experience health problems as a result of the strains of providing care. Recent research has highlighted that depression is higher among carers than the general population and there are emerging indications that the stress levels of carers are much higher than the person with the diagnosed condition.

Successful respite outcomes are therefore critical to the maintenance of balance in the carer's life. This has the double advantage of improving the quality of care to the person with Parkinson's as well as ensuring quality of life for the carer.

### **Current Experience of Respite**

Of the carers who had used respite, their experience ranged from a sub acute stay in hospital, to in-home and residential stays to day programs like exercise or men's groups. Their experiences were described as follows:

### **Positive Experiences**

The positive experiences were generally created when there was a sense of belonging and communication between the care agency and family. One carer reported that the facility staff met with her beforehand to sit down and discuss the situation and care needs, work through paperwork together, and answer questions. This was also intricately meshed in with the physical requirements of the condition being adhered and responded to (for example, facilities getting medication to the person on time, or the person being able to self-medicate and having the appropriate equipment available for mobility).

Consistency of staff also helped with relationship building, knowledge of the person receiving care and ability to provide more effective support.

In home respite worked particularly well when the person with Parkinson's was able to self medicate as Personal Care Attendants cannot administer medication, and district nurses are not able to guarantee being there on time.

Respite was also positive when the agency worked on interaction between people in the same circumstances (like social groups), with a focus being on activities that people would want to engage in.

*“My husband really enjoys the opportunity to meet new people and to socialise with others. He is a very intelligent man and likes to meet others with a diverse background.”*

*A two week respite was reported by one carer as very beneficial as it gave her husband the opportunity to ‘experience conversations with others outside the home’ because he was becoming fearful of not being able to do this any longer.*

One carer talked about a cottage style facility that was very good. What made it stand out was that it was a home like environment, with a maximum of 3 people there at a time. Each person receiving care had their own room and a greater opportunity for individual attention from staff.

Carers also found that their experiences of respite were more positive when they followed the recommendations about good facilities from other carers of PLWP.

Having staff who were educated and understood the complexities of Parkinson’s made a huge difference towards making respite a positive experience.

### **Negatives**

Negative experiences in respite mainly fell into three categories. The first, and most voiced problem with respite, was around medication administration and expertise of staff. Carers said that the medication needs of the PLWP were not met, which caused extreme anxiety for the carer and in some cases, caused a deterioration in the health of the PLWP. This was generally coupled with a low awareness and lack of insight among care staff about the needs of PLWP.

*“My husband (or nursing staff) would call everyday to report problems, so I never felt like I ever had a chance to escape my responsibilities.”*

*“I had to remember to call to remind the nursing home about medication. There was a lack of responsibility by staff for timely medication administration.”*

*“Meds were still not given 2 hours after they were due. I had to get a staff member from MDP Kingston to call the facility to talk to them about care needs. Kingston was very helpful but it didn’t help the care from the facility however.”*

There was also a problem with continuity of staff in both residential and in-home respite.

The second category of issues involved problems with access to respite, navigating the system, and respite not being appropriate to meet the needs of people with Parkinson’s. Carers found the process of dealing with many government departments intimidating and confusing.

Also, services available were dependent on locality, which gave the impression of a “Post code lottery”, so those living close to Caulfield, for example, were able to access sub-acute stays, whilst those in the Western region had less specialised services available.

*“I had had an operation and needed respite for my husband while I recovered. ACAS were not flexible enough to fulfil this need and I was left to struggle through my recovery as well as care for my husband.”*

In particular carers felt that some types of respite available did not allow them any freedom, as by the time they had dropped the PLWP off at the respite facility, it was time to come back again after only having done a couple of chores at home.

Carers were also concerned about the quality of respite as there was a very limited range of activities available, in most cases with minimal opportunities for

meaningful engagement with other people. Carers sometimes felt that they were punishing their partner in respite as they were confined to a chair and encouraged not to move around. One carer described the person receiving care becoming extremely isolated during the stay as there were no opportunities to engage with others.

Problems with the cost and issues with Centrelink were of particular concern. Centrelink was not considerate of the issues faced by carers in their role and is forcing some of them to take on work somewhere in between the immense carer duties. The **Welfare to Work** changes in particular were very frightening for carers – as the nature of Parkinson's means that thing will worsen over time and the carer burden will increase.

The third category of issues that contributed to a negative experience in respite was the behaviour of the person receiving care upon return home. Some carers felt that they were being punished by the person they were caring for after the respite as they didn't want to go in the first instance. One carer described difficulty in the person receiving care adjusting on their return home. Her husband would return very angry and take it out on her.

One carer described an incident where her husband had a period of a week in home respite while she went overseas and visited relatives. Upon her return, her husband had become totally withdrawn, refusing to open curtains, or turn on the television.

One carer described continuity of Home Care Workers as an issue. She said that once she had Home Care Worker trained up in her mother's routine (ie. creaming the legs etc), the workers had swapped and she had to start again. Working through a case manager who was not present at point of care was also frustrating.

These negative issues made carers feel insecure and anxious about accessing respite. It also led to a reduced uptake of respite services with consequences for the wellbeing of carers of people living with Parkinsons.

### **What carers want**

- Respite that fits in with lifestyle
- Sleep
- A break form the relentless nature of caring
- Someone to help them with all of the negotiation.
- Freedom
- Welfare Benefits and help with finances.

### **Some possible solutions identified by carers**

#### Medication / Staffing:

- Having Parkinson's Trained Staff at the respite facility
- Medication administered by registered nurses only
- Consistency of workers for in home respite.
- Paid carers being able to prompt the client for medication.
- More open communication channels between family carers and the paid carers – such as implementing diaries that can be used to improve communication between carers.
- Being able to negotiate with staff regarding the administration of medication (which gives freedom to enjoy the respite)
- Staff taking responsibility for any treatment needs that may arise – while notifying may be important, there should be no expectation of the carer having to take any action (ie. “Don't call me if J's urine has blood in it – you deal with it”).
- Increased staffing levels at the facility, particularly an increase in **qualified nursing staff**.

**What will improve the respite experience:**

- Including the PLWP and carer in the process and having a planned, easy to understand approach about how respite is delivered, --
- Offer alternatives to the current service delivery – have the system fit the person and not vice-versa.
- Having a holistic approach to care – like a ‘centre for excellence’, where one knows the people, is able to get all the services one needs and have a variety of different respite models which are all Parkinson’s specific (ie. Social support programs, in home respite, facility based respite, physiotherapy).
- ‘Provide respite in ‘day blocks’ so that one can achieve something that one wants to do in that time – not little two hr blocks;- ‘by the time you get out, you need to get back home again’.
- Make respite fun – and something that one would want to do! Like a bowls group – where all the people have Parkinson’s and no one is going to judge one or make one feel bad about being slow.
- Simplify paperwork
- Respite having more mentally stimulating activities rather than it being a place where one has to sit down all day.
- Including transport costs in the funding. Often the cost for attendance is prohibitive.. Transport also needs to be disability friendly.
- Booking slips to ‘bank’ respite and use when needed.
- Respite should be accessible regardless of where one lives and one should not be disadvantaged for living in the West.
- Having an advocate and someone to help with negotiating the system would be very useful.
- A system for recording recommendations from PLWP
- Regularity – knowing one has a day a week or every two weeks makes a huge difference - ‘gives me freedom’.

*“People need to know about the services that are available in the community to support PLWP and carers. Some people get told about certain options whilst others miss out – pot luck!”*

There is a need for better access to and understanding about aged care packages available (eg. Linkages, EACH).

### **Further scenarios**

The following comments by carers reveal the varied experience in relation to respite:

“I thought I had to use respite in order to get the foot in the door so that we would be eligible for permanent care in the future.”

One carer spoke about staff from the local service who would only come to provide assistance with showering and nothing else – such as providing prompts or reminders about medication. The staff are provided through the case manager who I is no present when problems occur.

“I have to call my husband during respite to ensure he takes his medication.”

“I was ‘forced’ to take weekend respite as a pre-requisite to permanent care. My husband was left in a chair the entire time, so I brought him home.”

“When I take my husband to bowls (informal form of respite) there is a lack of understanding of others about his limitations, and why it takes him longer to play.”

**Discussion**

*“The starting point for an appropriate service response for this group [people with Parkinson’s] 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.” (Fyffe 2007)*

Most carers named this issue as a key concern. If the medication regime is not properly administered, the whole respite experience degenerates in quality for both the person receiving care and the carer and compromises the health of the former. The major impact of this failure falls on the carer. This is a widespread concern among carers of people with Parkinson’s and it indicates a serious lack of responsiveness among service providers and is major deterrent to the use of respite services.

However, as this report indicates, this is not the only concern that carers have about using respite. Once a person is admitted to respite care, the responsibility for that person’s welfare rests with the facility. The purpose of the respite stay is to provide the carer with a rest from caring. If the carer’s respite is interrupted by calls from the facility (or the person receiving care) in regard to the care of their relative, it negates the purpose of the respite and its benefits. It is important also that the experience of respite be congenial for the person receiving care – hence stimulating activities, which are age and gender appropriate, are needed. When respite is not a happy or successful experience, it is the carer who bears the brunt of the dissatisfaction of the person receiving care – thus negating the desired respite outcomes.

**RESPITE WITHOUT TEARS – REPORT RECOMMENDATIONS****RECOMMENDED THAT –**

1. The findings of the Respite without Tears project be presented to key stakeholders, including the Residential Respite Network of the Victorian Carer Services Network, Parkinson's Australia and Carers Australia networks, as appropriate.
2. This initial phase be followed up with further discussions aimed at exploring areas for improvement and strategies to help resolve the current difficulties carers and people with Parkinson's experience in regard to respite.
3. A Best Practice model of respite care for people with Parkinson's be developed. The model could include the following elements:
  - Additional staff training to assist staff in addressing the special needs of people with Parkinson's.
  - A 3-way communication model involving the respite provider, family and case manager.
  - An Intake Policy involving family, respite facility and case manager designed to elicit accurate information about care needs, interests and stimulation.
  - The development of 'Medication Contracts' or other appropriate tool to ensure a correct medication regime for the respite user.
  - An Accreditation system giving recognition to facilities that have implemented the model.
4. The development of a Transition Support model involving support for carers and the care recipient in the transition into respite and the transition

to home following respite. This would include support for carers in addressing concerns about service as well as relationship issues as indicated in the project report.

- 5.** Parkinson's Victoria and Carers Victoria develop an education module for carers to assist them in addressing their concerns relating to achieving successful respite.
  
- 6.** Parkinson's Victoria and Carers Victoria continue to work on strategies to raise awareness of this issue among service providers and seek government support for implementing these reports. In particular, both organisations would work to develop and provide resources to provide a respite liaison worker to work with key stakeholders to implement the above recommendations is indicated.