



Care Alliance Ireland

The National Network of Voluntary
Organisations for Family Carers

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Parkinson's Association of Ireland

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Care Alliance Ireland and The Parkinson's Association of Ireland

The Caring Reality of Family Carers:

***An exploration of the health status of Family Carers of people
with Parkinson's disease***

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Executive Summary

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This report is available for download at www.carealliance.ie/publications.php

Information on the Research Partners

Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. We support organisations in their direct work of supporting Family Carers all over Ireland. We also provide information, education and training, regarding the needs of Family Carers; we carry out research relating to Family Carers, and promote inter agency collaboration.

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The Parkinsons Association of Ireland

The Parkinsons Association of Ireland is a registered charity, based in Dublin, with branches throughout the country. Our aim is to assist those with Parkinson's, their families, their carers, health professionals and interested others by offering support, a listening ear and information on any aspect of living with Parkinson's.

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About this research

Most caring in Ireland has traditionally taken place in the home. The health of family carers has not been a priority for the state even though it is crucial if people are to continue to provide informal care.

In 2008, the Care Alliance Ireland carried out a survey on the health of family carers. We felt that we should build on this by looking more closely at the factors which affect the health and well-being of carers. This research comes at a time when the Government has postponed the National Carers' Strategy in Ireland. In Irish society, the family unit is changing due to the economic downturn and other factors, such as migration and an aging population.

This research provides up to date information on the health and well-being of a specific group of family carers in Ireland – carers of people with Parkinson's disease. This follows our decision to carry out this research in association with the Parkinson's Association of Ireland. Around 7,000 people in Ireland have Parkinson's disease so their carers are likely to represent a sizeable sub-group of the 161,000 family carers identified in Census 2006. There is also very little research on the experiences of this group of family carers.

Aims and objectives of the research project

The overall aim of this research project was to explore the health status of a specific group of family carers. Family carers are people who provide physical or social care in the home to a family member with Parkinson's disease.

The specific objectives of this study were:

- To ask family carers what they consider to be the factors which affect their health
- To explore carers' needs in relation to factors affecting their health
- To ask family carers to identify what would benefit their health given their circumstances

How we carried out the research

How we selected participants

The Parkinson's Association of Ireland recruited participants through their large database of members. They targeted two geographical areas. We interviewed 20 family carers who are currently caring for a person with Parkinson's disease. Nearly three quarters of these were female and two thirds were aged 65 years or older.

How we collected the data

We carried out interviews at a time and place that suited participants. Interviews were semi-structured, which means the interviewer used questions to guide the interview but let the carer talk about issues they were concerned about. We also asked for information on the carers' age, gender, ethnic background and work status.

How we analysed the data

We recorded the interviews and transcribed them. The researcher then identified certain themes – issues that were raised by many of the participants.

Findings

As a result of this, we identified four main themes. These themes have a lot in common with the findings of the previous Care Alliance Ireland (2008) study and other research carried out in the area. These themes are:

The experience of the family carer

Many carers spoke of the severe physical demands and responsibilities of the caring role. They also detailed the emotional support which they provided. As the condition of the person with Parkinson's became gradually worse over time, the physical care they needed increased. The level of physical care needed could vary dramatically from day to day.

Newer family carers understood that their role would change over time. Many carers viewed caring for a person with Parkinson's disease as a long term role.

Carers' feelings towards caring differed. Many had a sense that they were expected to provide care because of their role in the family. However, some carers resented this sense of 'duty'. At the same time, few of them considered the option of residential care.

Some aspects of caring for a person with Parkinson's disease were seen as challenging. Some carers found helping with personal care was hard. Changes to the person's personality and behaviour as a result of Parkinson's disease were also difficult in some cases. The gradual decline in their condition meant that the carer's role was physically demanding and they needed to be there all the time. Carers found providing night time care was both upsetting and frustrating at times.

Carers used a range of coping techniques such as time for themselves, keeping up personal interests, taking exercise, contact with friends and getting support from others.

For many carers we spoke to, caring for person with Parkinson's disease led to major changes in the relationship between the family carer and the person they cared for. For instance, changes to the person's personality and behaviour. In several cases, the person with Parkinson's had also been diagnosed with a secondary condition such as dementia. Where the person's condition demanded very high physical care, the relationship consisted mostly of providing care. While still loving, the person with Parkinson's may not be able to reciprocate. Most carers felt that their main contribution to care was to allow the person to remain at home.

The impact of caring

For most people, their life before caring included time to themselves to pursue personal interests, with no need to plan in advance. Some had a sense of loss for what life had been like before they became a family carer. Many found that caring for someone with Parkinson's disease affected nearly all aspects of the carer's life. There were profound physical, emotional, social and positive impacts, depending on how severe the condition of the person was.

Many carers found the responsibilities of providing care to be both physically demanding and challenging, in particular at night time. As the condition got worse, the carer increasingly needed to be there all the time. A lot of family carers noted major changes to their daily routines. Some carers had to give up working outside the home but several continued to do this while providing care.

Many carers highlighted the impact on their own health and well-being. They considered the following conditions to be a result of the constant physical care they provided: high blood pressure, tiredness, lack of energy, back problems and arthritis. Several mentioned the lack of time for them to access the medical treatment they needed themselves. Some carers had been seriously ill themselves in the past, before taking on their caring role. Many expressed worry about what would happen to the person with Parkinson's disease in the event that the family carer became unwell.

Providing care to a person with Parkinson's disease had a strong impact on the emotional health of many carers in this study. Carers had feelings of frustration, unhappiness and loneliness as a result of the demands of their caring role. Some carers had experienced periods of depression. There was a feeling that the family carer was expected to be 'healthy', which may lead them to hide their true feelings or health status from other people. Many carers expressed feelings of anxiety and concern, with the person they care for constantly on their mind. They also worried about whether they could continue to provide care at home in the future as the condition got worse.

Providing care to a person with Parkinson's disease had a major impact on carers' social lives. Carers were limited in the time they could take for themselves and to keep up personal hobbies or interests, which lead to feelings of loneliness. Many saw friendships as an important way to make the most of the little time they had.

While the focus was mostly on the negative impact of family caring, some highlighted positive aspects of their role. Several carers believed they had become closer to the person with Parkinson's disease as a result of providing care and that it had benefited their relationship.

Support

Family carers identified many sources of support in their role. These came under the headings of formal, informal and financial support. The provision and levels of support they received had an impact on their family caring experience. Carers needed access to respite and day care services to give them a break. However, most said that existing respite services were not enough. Several carers received little or no respite because the person they cared for did not wish to go. Many carers had a sense of guilt when taking respite. Family carers said that home-based support through paid care workers was an important way for them to get a brief rest and take part in leisure activities, or even just do the shopping.

At the same time, carers raised issues about the inadequacy of current home-based support. Several carers had paid for additional home care support from the private sector due to these. The findings showed very different levels of support received from health workers. Many carers received little or no support from the public health nurse. Overall carers had a good relationship with their family doctor (GP) but some mentioned lack of support from GPs as a source of tension. Support from other health workers, such as occupational therapists, was welcomed and seen as beneficial. Family carers' relationship with health workers was not part of this study, but should probably be looked at in the future.

Many carers mentioned problems in accessing information on their entitlement to supports. Newer carers felt that they were still finding their way through the system. However, some people did not want to look for formal assistance.

Carers valued informal support from family members highly, although levels varied. Other family members also gave family carers a break from their role and allowed them to take part in other activities. When carers were not in good health, many depended on family members to provide care to the person with Parkinson's disease. On the other hand, some carers felt sad and isolated when other family members were not there. Some felt that other family members did not understand the needs of the carer. Some found it difficult to ask for help for fear of burdening other family members.

Carers who received support from voluntary organisations found it highly beneficial and a crucial way to access information, both on family carer issues and issues related to the condition. Carers saw support meetings as a way to gain knowledge, as well as a way to meet other people in similar situations.

There were some problems raised though. The distance to travel to support meetings was an issue. Joint support meetings for carer and the person they cared for were a problem. While some saw a support group just for carers as a possible solution, this would mean the need to have someone to take care of the person with Parkinson's disease so the carer could attend.

Carers condemned the levels of financial assistance from the state. They felt that the contribution made by family carers should be recognised by the state. As state support is so inadequate, some carers were trying to save money for future needs as the person's condition got worse.

Needs and interventions

Family carers made a number of suggestions that could be put in place to benefit their health. To maintain their own health and well-being, carers need a break from their role. They can do this with support from other family members, respite and day care services, and home-based support.

Some carers took regular exercise in order to have a positive impact on their own health.

Many carers felt that a support group just for family carers would benefit them, as a way of sharing information with fellow carers and also as a social outlet.

Many carers wanted a training programme for family carers that would help them in their role and have a positive impact on their health. They felt that it was essential to have the skills needed to deal with the emotional aspects of caring, and how to provide the higher level of physical care as the person's condition got worse.

Several carers did not think about their own needs or identify what they were. Others believed that the interventions outlined above would be vital as the person's condition got worse.

Key recommendations

1. Put in place the conditions needed for family carers to receive regular and sufficient time to themselves, which will enable them to continue in their role and have a positive impact on their health. To do this, there should be sufficient respite services and home-based support targeted at both the needs of the carer and person they care for.
2. Introduce a full assessment of family carers' needs. There is an urgent need to recognise and address carers' needs in their own right, alongside those of the person they care for. If care services are put in place with their needs in mind, this will maintain the carer's health and support them in their role. It is also important to consider the changing needs of the carer, as their role may become more demanding as the condition of the person they care for gets worse.

3. Improve informal support available to family carers. The voluntary sector must work in partnership to provide support services to family carers. For example, in the area of condition-specific training for carers and condition-specific carer support groups in order to maximise their knowledge and skills.
4. Introduce a health promotion programme for family carers. Family carers should be encouraged to look after their own health needs. One way to achieve this is through a nationwide annual check-up for all family carers, with equal emphasis on the physical and emotional health aspects of caring.
5. Introduce a public awareness campaign. There is an urgent need to improve awareness, understanding and recognition for family carers among the general public. This could be done through a media campaign at national, regional and local levels.
6. Make education, information, awareness and training of health workers on issues related to family carers' health a priority. All health workers must have a clear understanding of the role (and changing role) of the family carer in order to address their needs.
7. Set up an independent 24 hour help line for family carers. There is an urgent need for an adequately funded and independent help line that carers can access at any time of the day or night in a confidential way.
8. Provide adequate services to support the health needs of family carers when their caring role ends. Support measures must be put in place in order to improve the lives of carers when they stop caring. The physical and emotional health effects of caring may leave some carers finding it hard to cope with life after care, particularly those who may have been caring for several years.
9. All policy to support the health of family carers should be proactive rather than reactive. We must take steps to plan for the future support and health needs of family carers, particularly as their role becomes more demanding as the person's condition gets worse.