

Parkinson's disease: caring for the carers

A caring role is performed by one in every eight adults in the UK at any one time— and on average lasts for four years, with 40% of carers providing care for less than one year and 25% for more than 10 years. The peak age range at which caring begins is in the fifth and sixth decades of life.

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Carers are unpaid, non-professionals who provide help and support to people with physical and/or psychological disorders. An estimated 5.8 million people in the UK provide care for spouses, close family and friends, of whom 175,000 are aged under 18.¹ Whilst many articles acknowledge the value of carers in the journeys of patients with chronic disease, few give precedence to these passengers on the journey.

The carer's wellbeing is intimately related to the patient's health profile and subjective wellbeing: reducing the burden of caring for somebody with chronic disease may delay patients' placement in an institutionalised care and improve the physical and psychological health of both patients and their carers.² If only one in every 10 carers nationally felt unable to continue, it would cost the economy in excess of five billion pounds per annum.³ It is therefore of utmost human and financial imperative that we do not neglect these critical members of the healthcare team.

It is difficult to account for all the physical, psychological and social difficulties encountered by the carers of people with a variety of diseases, from schizophrenia to rheumatoid arthritis to chronic renal failure. Therefore, in this article, precedence to the hurdles faced by carers of people with Parkinson's disease will be demonstrated. Through the carer's perspective, we can explore the consequences of caring for a loved one, identifying factors that impact upon the burden of caring, and conclude with a discussion of how we as healthcare professionals might help to alleviate that burden.

In preparing this article, several carers of patients with Parkinson's disease have been interviewed, all of whom are at different stages of the caring role, and two of their stories have been cited (Box 1 and 2). It must be stressed that although these accounts provide some insight into their lives, there is no way of predicting how any individual will be affected by caring for a loved one or which aspect of the illness

will be most challenging to that particular carer.

Most carers have not chosen to be in their position, nor had any prior preparation for this taxing, life-changing role. It is a role few would voluntarily undertake, testing the limits of patience and tolerance, with little time off. The burden of caregiving results from the "physical, psychological, emotional, social and financial problems experienced by families caring for older adults."⁴ Nevertheless over half of all carers find their role "rewarding", gaining immense satisfaction from meeting cultural or religious expectations, and only 10% consider it a burden, the remainder regarding their role equally rewarding and burdensome.⁵

A diagnosis of a chronic neurological condition, such as Parkinson's disease, may be met by the patient and carer alike with emotions ranging from relief that a biological diagnosis has been identified, disbelief and denial, to sadness and fear of the future. Similar emotions may be evoked amongst family and friends and a previously unrealised wealth of practical and emotional support may be unearthed. However, we should realise and respect the fact that some people may choose to distance themselves from both the patient and carer, compounding feelings of alienation and underlining the unpredictability of different people's reaction to the same news.

Motor difficulties encountered by the patients can deteriorate with time and often force the patient to retire or stop driving earlier than they would like. If the patient develops increasing difficulty in performing their activities of daily living, established roles may be reversed: female carers may start doing the gardening and repairs around the house, and likewise male carers may start cooking and cleaning for the first time. The carer may then feel compelled to reduce their work to part-time or give up work entirely, with a concomitant loss of self-satisfaction and self-worth derived from work and the severing of an important means of contact with the outside world. Carers of patients with Parkinson's disease are less likely

Box 1: Case study

Mr X is a 72 year old former shop manager, whose 65 year old wife Mrs X was diagnosed with Parkinson's disease four years ago. At the time of diagnosis, Mrs X's speech had become slurred and she was walking with small shuffling steps. Mr X accepted the Parkinson's disease diagnosis more readily than his wife, and has since assumed the role of primary carer. Following an occupational therapy assessment, Mr X has had to pay for adaptations that have been made around their bungalow, including handles in rooms and a hydraulic lift in the bath. Mr X feels sorrow at Mrs X's frustration that she is not able to perform the tasks she once was able to, and guilt that he now begrudgingly performs the menial tasks that his wife longs to do, such as cooking and cleaning. Although their children visit more frequently, Mr and Mrs X have found their social life has been impaired by the Parkinson's disease, having to cancel outings such as restaurant bookings and theatre trips at short notice should Mrs X have an "off" period, and the difficulty in moving Mrs X in and out of the car when attending the weekly bingo has meant that they have stopped going.

to get out of the house, have a holiday or have contact with friends and neighbours.³ The unpredictability of an "off" (or "frozen") phase, when the patient is taking medication, may mean that theatre trips and restaurant bookings are begrudgingly cancelled at short notice, incurring financial expense and personal disappointment.

Depression

Depression is widely recognised as being more prevalent amongst spouse carers⁶ and children⁷ of adults with Parkinson's disease than in the general population, and is correlated with the duration of the patient's symptoms.⁸ Carers of individuals with profound psychological changes, such as confusion, hallucinations, dementia and depression, are at particular risk.⁹ Compounding the depression may be anticipatory bereavement of the person they once knew and the reciprocal relationship they once shared, together with feelings of embarrassment, overload, guilt, entrapment and uselessness. GPs should actively seek depression in people identified as carers, and instigate cognitive behavioural therapy¹⁰ or pharmacological treatment.

Physical health

Almost half of all carers of patients with physical disabilities attribute musculoskeletal problems, commonly back pain, to their caring role. However, a 2003 meta-analysis showed that whilst the risk of physical health injury is higher amongst carers, the difference is not significant after accounting for age and pre-existing morbidity.⁴ The caring role is more strongly related to objective, less well-defined measures of poor health, such as hypertension, raised levels of

stress hormones and an impaired antibody response to infection, strongly suggesting that there is a biological detriment to carers.

Younger carers (under the age of 65 years) often have better physical health than their older counterparts, but report greater burden, and have a worse psychosocial profile and greater risk of depression.¹¹ This has been postulated to be due to the competing demands of caregiving with those of maintaining their job and caring for a younger family. Adult children may become preoccupied with the thought of who will care for their parent in the future, and may prematurely and unnecessarily brood upon the prospect of being diagnosed with Parkinson's disease themselves.

Carers can feel that they are undervalued by care-recipients and the healthcare profession, and often rely upon friends and family for support.¹ Voluntary organisations, either specifically for certain diseases or for carers as a group can also provide a huge source of comfort and support, affording an additional social outlet and a forum in which grievances can be aired and tips on how best to deal with aspects of the illness can be shared with others in similar predicaments, as well as practical assistance, such as another carer volunteering to sit with the patient whilst the primary carer performs weekly errands.

Adequate information provided at an early stage may allay some of the fear and uncertainty, and allow patients and carers alike to prepare for the impact of Parkinson's disease upon their lives. Much information can be gleaned from the internet and from books. Where available, a specialist Parkinson's disease nurse can act as this fount of knowledge, dispensing practical advice and support at all stages of the illness. The physiotherapist treating the patient is able to give rudimentary training in manual handling to the carer, to avoid care-related musculoskeletal injuries.

Box 2: Case study

Fifteen years ago, Mr and Mrs Y were both in their early 40s with two young children, when Mr Y was diagnosed with Parkinson's disease. Although he felt unable to continue in his job, Mr Y was able to work for a further 12 years to help repay their hefty overdraft.

An episode when Mr Y fell and was unable to get up until Mrs Y returned home forced Mrs Y to become her husband's fulltime carer and receive the Carer's Allowance. She feels angry that her husband, who previously led an active, healthy life, should be so cruelly affected by the disease, and both resentful and humiliated that she should have to give up the job she enjoyed to "scrounge off the state". Mrs Y also worries about her elder son, who is perpetually preoccupied with the prospect of being diagnosed with Parkinson's disease himself and cannot motivate himself to achieve anything, educationally or socially. Only recently, when she broke down in tears at her surgery during a routine blood pressure check-up, was her depression recognised and antidepressant tablets started.

The hardest aspect of the illness for Mrs Y has been balancing the caring role, with her job, whilst trying to maintain a normal quality of life for the family. It has saddened her that not once has she received acknowledgement of this juggling act by her husband or the healthcare professionals involved in his care.

Support

From the medical profession, carers need three things: recognition of their role, information and support.¹² GPs and hospital clinicians can establish who is doing the caring for each patient and acknowledge their role on subsequent visits. A simple question, such as "How are you doing, Mrs Brown?", is often greatly appreciated by the carer. Also welcomed is recognition of carers' concerns about the patient and an opportunity to participate in decision making, where this does not contravene the wishes of the patient themselves.

Social workers can provide financial advice, and together with supportive employers may facilitate continuing employment, thus maintaining self-esteem and contact outside of the home for both patients and carers. This may be achieved through flexible working, allowing time off for hospital appointments or unexpected medical emergencies, or by altering particulars of the job, making it more amenable to caregiving.

Following recent legislation, carers are entitled to an annual assessment of their caring, physical and mental health needs, and an individualised care plan drafted by a care keyworker.¹³ Such care plans provide information on what a carer needs to fulfil their role and protect their own health and how the most appropriate resources can be readily accessed. Additionally, care plans contain contact information for support groups and organisations and may make arrangements for respite care. Whilst some carers may be reluctant to be labelled as such, by acknowledging their role the particular difficulties they face can be more readily addressed.

Whilst the primary caring responsibility may end if

a patient is placed in a nursing or residential home, the carer often continues to provide emotional and financial support for the rest of the patient's life. Following the death of their loved one, carers may feel a huge void in their lives which they are uncertain how to fill, and a second wave of depression may ensue. At this time, healthcare professionals must continue to respect the right of their patients to individuality: whilst support organisations or bereavement counselling can help some, others prefer to deal with their grief themselves, whether that is through personal contemplation, spiritual reflection or sharing their sadness with family and friends.

Conclusion

A diagnosis of a chronic incurable disease impacts immeasurably upon the patients, but also holds profound implications for the millions of partners, close relatives and friends who are caring for their loved ones. As society ages, an ever-increasing number of us will be assigned the caring role. Health professionals must be sensitive to the individual requirements of carers and consider how the caring role impacts upon their employment and social lives, as well as their physical and mental health. By engaging in effective multidisciplinary teamwork to meet the health needs of these "hidden patients,"¹⁴ we can benefit millions of carers, the recipients of their care and society as a whole.

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