

Parkinson's Disease Society Time to Care for Carers



This report is intended to profile the work of carers and outline practical help and guidance for carers who care for someone with Parkinson's disease. The Parkinson's Disease Society (PDS) recognises that carers play a vital role in providing care and support for many of the 120,000 people with Parkinson's in the UK.

Caring for someone with Parkinson's can be demanding socially, psychologically, and physically. Caring can also be rewarding and fulfilling and because of the understanding a carer has of the needs of the person they are caring for, it can also empower them to become involved in influencing decision makers and campaigning for change.

Research by the PDS shows that over three-quarters of carers who look after someone with Parkinson's have a health problem and many report more than one. The most commonly reported problems are arthritis (48%), anxiety/nervousness (33%) and heart, blood or circulatory problems (30%). Despite this, only three out of five people who care for someone with Parkinson's receive help from the local authority or social services.¹

Children and young people can also be affected by Parkinson's, by living with or having a relative with Parkinson's, and they can sometimes become involved in supporting their relative, either on their own or with other members of the family.

Some of the issues facing carers include:

- *Appropriate support services – 'I was always*

needed to be there...' – there should be comprehensive support services in place throughout the UK based on the assessment of carers' needs.

- *Respite care – 'I have been ill a couple of times and there was no-one to help.' – carers need planned, appropriate respite care services and appropriate rapid response support should be available to help in times of crisis.*
- *Social support and sharing experiences with others – 'It's really very helpful to talk to other carers. You share your experiences....' – support and social interaction including regular short breaks can greatly reduce the feelings of isolation faced by some carers.*
- *Information to access appropriate services and advice – 'At first when I needed help I didn't know where to go or what to ask' – carers need to be provided with information and signposting to the appropriate services and advice.*
- *Finances – 'we also need a lot of financial backup...' – the support and benefits available to carers need to be strengthened and accessible.*

The PDS have produced this guide to highlight the key role of carers and the issues they face. It provides practical advice and guidance and gives details of the services the Society offers and where further help can be found.

If you need further information or assistance please do contact us.

**Linda Kelly, Chief Executive,
Parkinson's Disease Society**

Parkinson's Disease and Carers

With Parkinson's one never knows the minute help will be required so as a carer I'm on call 24 hours a day, seven days a week. I have to do the things that Ina can't. I need to help Ina dress, wash, undress, help her into bed, out of bed, help her turn in bed. Things are so terribly unpredictable that one just lives minute-by-minute.²

It is an illness that affects everyone in the family. It is lonely because you do lose friends and you can't make arrangements to do things and go places.³

Parkinson's disease is a progressive neurological disorder affecting 120,000 people in the UK.

Up to 500,000 people live with Parkinson's as partners or family members who provide care and support.

Parkinson's disease:

- **Affects people of all ages and is debilitating and degenerative**
- **Is unpredictable in its effects by the day and hour and affects each person with Parkinson's (and the life of each carer) differently**
- **Is presently incurable and the longer someone has Parkinson's the more care they are likely to need**

Parkinson's Disease Society

Time to Care for Carers

- Is treatable with medication but this is often complicated by side-effects, which are difficult to manage, and are often misunderstood
- Can be associated with age related illnesses and dementia⁴

Research has shown that if carers are not aware of or do not understand the disease process, the management options, the medication regimens and the side effects, then management outcomes are less likely to be positive.⁵

Addressing Carers' Issues

It's a hard life, it's not a terrible life. We're caring for people we love. But we want, not that negativity, but constructive help. We need a lot of emotional backup...we also need a lot of financial backup.⁶

Services providing quality health and social care acknowledge the Department of Health's (England) *National Carers Strategy*⁷ and adhere to the five principal standards of a quality service:

- Information
- Respite
- Emotional Support
- Care for the Carer
- Having a voice that is respected

The PDS addresses carers' issues in many different ways, working with these principal standards as appropriate to the work we are developing, planning or providing. These are outlined below.

PDS National Services

The PDS provides information and advice to help carers with any issues they have relating to Parkinson's and caring and often signpost them to other organisations such as Carers UK, Crossroads – Caring for Carers, and the Princess Royal Trust for Carers. Our services include:

Helpline – 0808 800 0303: The PDS's confidential Helpline service is available Monday to Friday, 9.30am–5.30pm (except Bank Holidays)

and is staffed by specialist nurses who offer advice, information and support to anyone affected by Parkinson's. The Helpline is also available for enquiries from professionals working with people with Parkinson's.

Welfare and Employment Rights Department:

The PDS Welfare and Employment Rights Department can advise on issues such as finance, disability and welfare benefits, insurance, employment, disability discrimination, disability rights and access to local advice agencies throughout the UK. The service provides a number of free information sheets on welfare benefits relevant to people with Parkinson's and carers.

For further information or advice please contact Angela LaTouche on 020 7932 1340.

Publications, Information Sheets, Audio-Visual Resources:

The PDS recognises that Parkinson's does not just affect the person with the condition. Anyone living with someone with Parkinson's or caring for them needs information and support. The PDS has developed a number of widely used resources for carers of all ages which are listed at the end of this leaflet.

For further information please contact Colin Cosgrove on 020 7932 1316.

Education and Professional Development:

Our professional development team provide seminars for carers which, in confidence and safety they can learn more about Parkinson's and its management, develop strategies for care, while sharing experiences with others in a similar position.

We have also developed *Healthcare for Carers*, an educational pack for carers, hospital teams, primary care groups and surgery teams, funded by a sponsorship grant from Pharmacia.

For further details please contact Morven White on 0141 943 1760.

Research⁸: As well as an extensive research programme on basic and applied science, the PDS funds many research projects on health and social care issues. Current studies funded by the

Parkinson's Disease Society Time to Care for Carers



PDS, which involve carers' issues include:

- Identifying the needs of people living with Parkinson's when the disease process becomes more complex and challenging⁹
- Carers focus groups and patient/carer involvement programme
- A randomised control trial of cognitive-behaviour therapy for carers of people with Parkinson's
- Quality of life issues for children who have a parent with Parkinson's
- Analysis of sexual and relationship dysfunction in people with Parkinson's and their partners
- Impact of falls due to Parkinson's: the carer's perspective

*For further information please contact
Caroline Murphy on 020 7963 9313.*

Campaigning and Local Services and Support:

*It's really very helpful to talk to other carers.
You share your experiences and actually saying it
seems to get it out of your system. Also someone
will say I've done this and it helps.¹⁰*

*I have been ill a couple of times this year and I have
tried all the resources... and there is no-one to help.
That does worry me because I feel they don't always
understand the medical side of Parkinson's and
I think who is going to love and care for him...
I'd love to think he was going into a home that is
caring and loving for him.¹¹*

The PDS aims to influence the Government and key policy makers to campaign on issues to benefit the lives of people with Parkinson's their families and carers.

The PDS also has staff working locally across the UK, including Northern Ireland, Scotland, and Wales. Their aim is to ensure that people with Parkinson's, their families and carers have better access to and improved quality of services locally. We have over 300 branches with 3,500 volunteers, who provide support in a number of ways to those affected by Parkinson's.

Carers Organisations

Princess Royal Trust for Carers

142 Minories, London EC3N 1LB

Tel: 020 7480 7788

E-mail: info@carers.org

Website: www.carers.org

Carers UK

20-25 Glasshouse Yard, London EC1A 4JS

Telephone: 020 7490 8818

E-mail: info@ukcarers.org

Website: www.carersonline.org.uk

Crossroads – Caring for Carers

10 Regent Place, Rugby, Warwickshire
CV21 2PN

Tel: 01788 573653 Fax: 01788 565498

Website: www.crossroads.org.uk

PDS Resources for Carers

A Carers Guide (B71) – free

(Also available on cassette tape)

Funded by a grant from the Diana, Princess of Wales Memorial Fund, this provides information on key issues that affect carers such as meeting needs, getting support, respite care, finance, and recognition.

Carers' Assessment (FS46) – free

Under the Carers (Recognition and Services) Act, 1995, carers are entitled to separate social services assessment of their needs. This sheet provides information on carers' assessments and tips on preparing for one.

No More Secrets video (V7) – price £21

This video aims to answer many of the common questions and concerns new carers have. It includes contributions from carers who talk candidly about their experiences and offer practical, clear advice and encouragement for other carers.

The Long Term Parkinson's Carers Companion – An A-Z Guide video (V9) – price £23

Using an accessible A-Z format, this video gives long-term carers of people with Parkinson's,

Parkinson's Disease Society

Time to Care for Carers

practical information to help them with some of the common problems that they may experience.

For Young Carers

Gramps has Parkinson's/Grandma has Parkinson's (B39/B40) – free

Two illustrated booklets for young children explaining how the condition may affect a grandparent. Urdu, Gujarati, Punjabi and Afro-Caribbean versions are also available.

Our Mum has Parkinson's (B38) – free

An illustrated story book for 3-11 year olds, written by a teacher who has Parkinson's.

Understanding Parkinson's: A Guide for Young People (B43) – free

An illustrated guide for 10-15 year olds, which explains Parkinson's, how it affects people, and how it is treated.

NB there is a P&P charge of £1 for up to 5 items.

The P&P charge applies to ALL orders.

All resources are available from the PDS distributor, Sharward Services, Westerfield Business Centre, Main Road, Westerfield, Ipswich, IP6 9AB; Tel: 01473 212115; E-mail: services@sharward.co.uk

To find out more please contact:

PDS National Office

215 Vauxhall Bridge Road
London SW1V 1EJ

Tel 020 7931 8080 Fax 020 7233 9908

E-mail enquiries@parkinsons.org.uk

Website www.parkinsons.org.uk

PDS Helpline Tel: 0808 800 0303

Textphone (Minicom): 020 7963 9380
(Monday – Friday, 9.30am – 5.30pm)

¹ Yarrow S, Survey of Members of the Parkinson's Disease Society, 1999, *PDS and Policy Studies Institute Research funded by the PDS*

² Pendrey M (long-term carer of his late wife Ina) – GMTV Get Up and Give Appeal video, 1996

³ Blackwell L (long-term carer of her husband John) – The Long-Term Parkinson's Carers Guide video, PDS, 2000

⁴ Buchanan S and Willis E, The Guide... for those who care for people living with Parkinson's, PDS, 2000, funded by the Princess Diana Memorial Fund

⁵ Von Korff M, Glasgow RE, Sharpe M, Organising Care for Chronic Illness, *BMJ*, 2002, July 13; 325 (7355): 92-4

⁶ Lewis A, *Parkinson's Disease: The Personal View video*, PDS, 1990

⁷ Department of Health, National Strategy for Carers, 2002, which can be viewed at website: www.carers.gov.uk/

⁸ See the PDS publication, *Seeking Solutions*, for more information on the PDS research programme or contact the PDS Research Department

⁹ Research funded by the Wolfson Trust

¹⁰ Henderson D (long-term carer of her late husband Rowland), The Long-Term Parkinson's Carers Guide video, PDS, 2000

¹¹ Bristow, K (long-term carer of her late husband Tom), *Parkinson's Disease: The Personal View video*, PDS, 1990