

Caring for the Carer

Bridget McCall provides a checklist for carers to help them cope with their demanding role

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Carers play an extremely important role in the lives of many people with Parkinson's, by providing much needed practical and emotional support. When the person is in the early stages, this may mainly involve giving encouragement and an occasional helping hand. In the later stages, however, it may include helping them with many daily and personal activities, such as washing, dressing, eating and managing medication.

Most carers desperately want to care for the person they love and, despite the challenges, it can be a very rewarding experience. However, it can also be an extremely hard life, especially where the carer feels isolated, is struggling to make ends meet or has little support.

The needs of carers are as important as those of the people they are caring for, yet they often get neglected because attention tends to focus on the person being cared for. It is vital that carers maintain their own

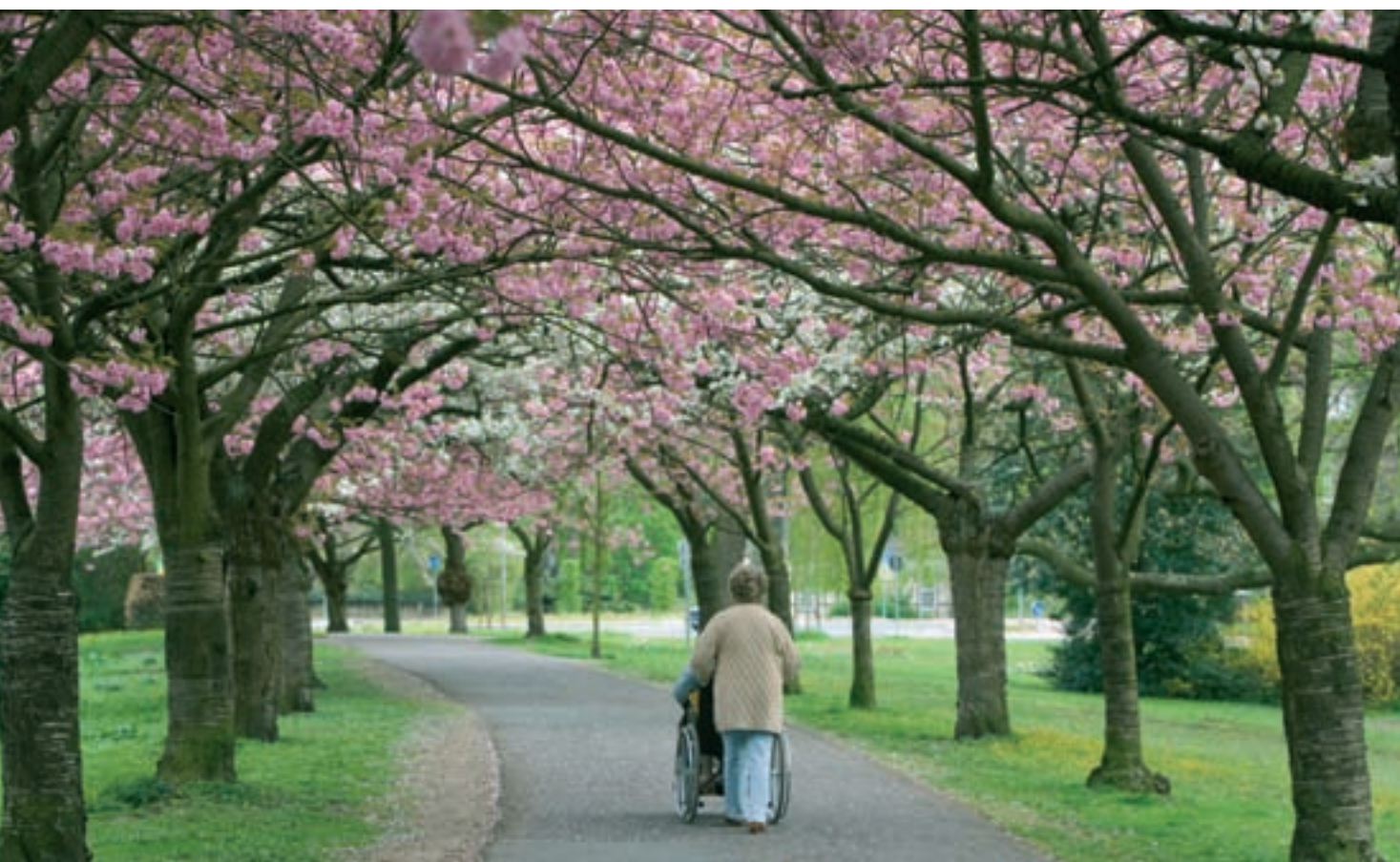
health and well-being while caring, if they are to cope with the challenges that caring presents them with. This is something that health and social care professionals involved in their care can encourage by giving them the following checklist of carers' tips.

Checklist

1. Getting information

Make sure you have the information you need. As a carer you usually need information to help you care for someone and to support you as a carer. Your local Parkinson's association and any carers organisations that exist in your country should be able to advise you on what is available and give you leaflets, booklets and other resources. The EPDA also publishes many useful resources on their website – <http://www.rewritetomorrow.eu.com/en/QoL-issues/Carers/furtherInfo.htm>.

The health/social care professionals you are in contact with are also important sources of support and information.



2. Social services

Make sure you have access to any health or social care services that are available to you – including anything that is provided specifically for carers. Ask for a social services assessment for the person you are caring for and a carers' assessment for you. What there is and how you access it will depend on arrangements in the country you live in. Your doctor or the local Parkinson's organisation should be able to provide you with more information.

3. Keeping records

Keep a diary or record of the symptoms and difficulties that the person you are caring for has, and the details of your caring role. This can help you keep track of how living with disability or illness affects you and assist you when communicating with health and social care professionals.

4. Financial help

Check what financial benefits you are entitled to. Your local Parkinson's organisation should be able to provide further advice or signpost you to sources of information about any financial benefits that may be available to you and the person you are caring for.

5. Dealing with emotions

Accept your feelings and talk about what you are doing. Don't be surprised if you have complex, conflicting and fluctuating emotions about caring, even if you love the person you are caring for very much. Talking about your feelings and what you are doing is important. Some people prefer to talk to the person they are caring for or to family and friends. Others find it helps to talk to someone who is not so closely involved in their lives, such as a counsellor, helplines or support groups.

6. Networking and support

Try to have contact with other carers. Many carers find contact with other people who are in a similar position is the key to survival, providing invaluable mutual support, information, ideas and friendship. There are many ways to do this, including support groups at your local Parkinson's or carers' organisation, telephone-befriending networks and Internet forums.

7. Encouraging independence

Wherever possible, promote independence on the part of the person you are caring for, even if this means activities take longer. This will improve their self-esteem and ease your caring responsibilities.

8. Asking for help

Make it clear what you are willing to do. Set priorities and don't be afraid to ask for help when you need it. Sometimes breaking down large difficulties into smaller, more manageable pieces can help.

Don't assume because you are a carer that you have to do everything single-handedly or every task that is needed. Although it may seem impossible, alternatives can often be found for the aspects that you are not able or do not want to do. Any health or social care professionals you are in touch with may be able to help you find solutions.

9. Looking after yourself

Make sure you maintain your own health and keep time for yourself. You should try to eat well, exercise regularly, learn relaxation techniques and have regular breaks from caring. This involves taking advantage of any respite care facilities that are available to you in your local area.

If you find your responsibilities overwhelming or you feel depressed and exhausted, talk to your doctor as a matter of urgency.

10. Taking time off

Don't make caring and the health condition in question the sole focus of your life. Make sure that you and the person you are caring for have things that you like to do together that are not about Parkinson's or health. Having times away from each other to pursue individual interests is also important.

11. Maintaining a lighter perspective

Try to keep your sense of humour. Many carers say that keeping their sense of humour and seeing the funny side of things has helped them and the person they are caring for enormously.

Further information

This article is based on information contained in *The Complete Carer's Guide* by Bridget McCall. This is a general, practical guide to caring. Published by Sheldon Press 2007. Price £7.99 ISBN: 0859699951.

Many carers also recommend *The Selfish Pig's Guide to Caring* by Hugh Marriott, who cares for his wife Cathie, who has Huntington's disease. This book explores, often in a brutally frank but amusing way, the mixed feelings carers have about caring and discusses subjects that can be difficult for carers to broach with health professionals. Published by Time Warner Paperbacks 2006. £8.99 ISBN: 0751537098.

Eurocarers is an EU-wide organisation that has been set up to raise awareness of carers' needs and encourage the development of specific services. See www.eurocarers.org/