

This document is a compilation of extracts from the 'Caring for YOU!' series of magazines for caregivers. Our thanks to AbbVie for permission to share this content.

Managing change

Top tips to help you cope with the changes that may come when Parkinson's disease progresses.

With the changing nature of the disease, you may have to reassess your routines and start working out how you may need to adapt or adjust some aspects of your life.

You may not be a qualified health professional, but you are the most qualified person who is capable of noticing any changes in your loved one's condition. That means that you're in the best position to judge how their care needs are changing and what extra help they – and you – may require.

What might change?

Your routines

People with Parkinson's have a range of different needs and these can change over time.³

'You may notice that as the symptoms of the person you're caring for change, they will become less independent. That may mean that your regular routine gets broken as you both adapt to the extra responsibilities that are falling on your shoulders,' says Health Psychology Specialist Clare Moloney.

'Accepting the changing nature of the condition – and the extra workload that comes with it – may be hard, but it's a key step towards moving forward and developing new routines to help you in the future.'

Adapting to changing treatment

It is common for a person's treatment plan to evolve as their condition changes or deteriorates – this is to ensure they are on the best treatment option based on their unique circumstances.² That means that as well as helping to make decisions about adapting to new treatments and dosing, you will have to learn how it works, how to manage it and how to make it part of your daily routine.

Changes in your relationship

The nature of Parkinson's disease may have an impact on your relationship with your loved one, and at times, it may feel like you have become more distant from each other.

If the person you care for is your partner, your physical relationship may well change too, with tenderness taking the place of intimacy. Seeing your relationship change in this way can be upsetting, and there isn't any right or wrong way to manage it – talk openly together to maintain your closeness. Making the most of every day may sound like a cliché, but it may help to try and enjoy the time you have and what you can do together – especially the relief that a change in treatment may bring.

Changes in you

As the condition progresses, the extra workload on you may take its toll. You may have even less time for yourself and this can affect your moods and emotions, and lead to stress and anxiety.⁴ If at any time you are finding it hard to cope, then ask for help from your own healthcare team, from other members of your family, and from friends.

“Making the most of every day may sound like a cliché, but it may help to try and enjoy the time you have and what you can do together.”

Staying realistic

Some of these changes may be difficult, especially when they have such a direct impact on your day-to-day life.

‘However, while you probably put on a brave face and don't like to admit it, you've probably already overcome other difficult challenges in recent times,’ says Clare. You can use these experiences to help you deal with these new changes and to keep going.

Everyone who cares for someone has developed his or her own system and routines. Why not get in touch with other carers for advice about how they cope and the strategies they use? Sharing experiences is a great way to learn new ways to manage day-to-day.

‘Just remember, though: ask for help when you need it. Whether it's a few hours for some time out for fresh air and exercise, or a day (or longer) off, managing to find time for yourself will be part of the solution of balancing your new routine.’

References:

- 2 EPDA. Advanced Parkinson's Pathfinder. In. 2013.
- 3 Eurocarers. Carers in Europe Factsheet. In.
- 4 Narum LT, N. Caregiver Stress & Coping: The Journey Through Caregiving. In: (Project NDFC, ed): North Dakota State University. 2003.