

Do you live with or care for someone who has Parkinson's?

No two people with Parkinson's are the same. So, the following is intended to help with some symptoms and not be a list of things to expect. It is a document created from observations and information gathered from many sources over 17+ years, primarily spouse, carers, friends, and family and as working as a support worker and 5 years as a personal assistant for people living with Parkinson's

So, let us begin by looking at Parkinson's as understanding some of its unusual symptoms can help to understand behaviors and lessen stress and/or frustration.

Thinking big but actions small.

Parkinson's is primarily a lack of Dopamine, or in brief – the chemical messenger in the brain responsible for delivering all the instructions to every muscle in the body. As the Dopamine depletes due to Parkinson's the messages get weaker, lost or broken, hence the slowness, rigidity, tremor etc.

What is difficult to understand, is that to the person with Parkinson's, their actions often feel the same as they always have. I often see people who were only aware they were dragging their feet or shuffling when you show them the abnormal wear on the soles of their shoes. They feel like they are lifting their feet 8" to clear a 6" step but they are only lifting 5" and catch the step every time. They often feel they are talking perfectly well but their voice is softer and people are always asking them to speak up.

Word finding or losing their way mid-sentence.

Cognitive slowing is very common but should not be confused with dementia. Avoid finishing the sentences and allow time so they can be part of conversations. There is a recognised increased chance of memory issues and dementia with Parkinson's, so any signs or concerns should be referred to their Parkinson's team or GP.

This is a small example but I have seen how frustrating this can be for couples and how beneficial it is to have that understanding.

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Anxiety.

In my opinion, the most understated symptom of Parkinson's and often the biggest obstacle to keeping well.

It is important to recognize that dopamine is not just responsible for carrying messages across the brain to every muscle in the body, Dopamine is also a reward or feel-good chemical. If the levels of dopamine are lower than it should be, then it is expected that mood will be lower too. This often manifests itself in the form of anxiety, apprehension, dwelling on minor worries, making mountains out of molehills and can become depression.

It is not unusual to find people have been treated for anxiety and depression many years before they are diagnosed with Parkinson's only to come off the treatments when they receive a Parkinson's diagnosis as they realise the way they felt is not their fault and now they have a name they can deal with it easier.

An example of the negative effects of Parkinson's anxiety.

So, the person with the condition may learn that there is a group, exercise class, coffee morning etc. that seems perfect for them. But watch out for the Parkinson's anxiety that will probably provide them with a whole myriad of reasons not to go by the time the event comes around, (I may not like it, I may see "my future" I may see someone I know, I may see no-one I know, I may not be able to park close, it may be rainingand so on) only to make them feel worse after when they think "I wish I had gone and given it a try" and then they beat themselves down for not going.

So, encourage them to **not let Parkinson's define who they are**. Give anything a try, their presence *and yours* will be very welcome, and if it turns out not to be the best thing, then try something else. By attending any of these groups or events, commits to nothing. You may come or go as you please, and most events are free or of little cost. Do not forget just by turning up, you help others. And many events and groups welcome family, spouses, and carers. So, the person with Parkinson's does not even need to go.

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Panic attacks.

Often any anxiety or stress, excitement etc. will exacerbate Parkinson's symptoms. This can in turn lead to more anxiety, stress, self-consciousness, embarrassment etc. and can snowball to become an all-consuming state of stress, rigidity, and inability to initiate or control movement. This can be triggered when a person "goes off" or medication benefits wear off before the next dose is due. But it can be just that the anxiety is such that it is stronger than the benefits from the medication. Relaxation techniques can help with these situations, including breathing exercises, relaxation CD's etc. but it is important to find what works best for the individual.

Single tasking/ less feedback

As a man, I am always told I cannot multi task anyway! But this is much more of a feature across the sexes when someone has Parkinson's. The Parkinson's specialist may have mentioned that focusing on one task at a time helps to perform that task at its best. So, for example focus on the walking not the talking. If they walk and carry a cup of tea, they might walk well but the tea spills, or if the tea is the focus, the walking may be a little more precarious.

Parkinson's is known to affect the Executive function of the brain, making decisions, planning, structuring, and assessing the consequences of actions all become more challenging. This can, after many years, drive the single tasking in some people, so they will focus purely on the goal without considering the consequences or risks.

E.g., A spouse tells their partner to sit and rest while they take a shower as they tend to fall. The spouse goes into the shower, the partner decides to do a crossword whilst waiting, gets up to get the crossword from the magazine rack and falls. This can be *solely* as the action was not thought through, or a combination of this, symptoms, and/or a wish to be independent, with no intention to upset anyone.

Unfortunately, with the actions as described above, there can be a considerable impact on the carer/spouse. As there was no sequential planning and little or consideration of consequences.

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So, the thought became – “get crossword” whereas a more structured line of planning may look something like: -

I would like to do a crossword but I cannot risk getting up on my own as I may fall and injure myself – which would mean my spouse may have to help get me up/ or call someone in/ get treatment for my injury/ be unable to relax when I am out of their sight in case, I do the same thing again etc. etc.

Because of the reduced ability to plan, analyze etc.; we do hear of spouses/careers receiving less in the way of feedback, gratitude, appreciation, affection. This may be also exacerbated by the person with Parkinson's feeling of less value. But either way, it is very difficult for someone to give so much without having something back to keep them going.

Inhibition.

Although quite rare, and almost certainly linked with the above. Some spouses/carers have noticed a change in inhibitions. Often displayed as inappropriate language or behavior. Again, this is not often apparent to the person with Parkinson's but can be uncomfortable in social situations and difficult to explain. It may mean some social situations are then avoided due to concerns around behavior and this can impact further on the wellbeing of those caring and cared for.

Who is the expert.

That will be you. You are probably the person who spends the most time with, as well as the one who knows and understands the person and there symptoms best.

As mentioned earlier in this leaflet. You may see things that the person you look after is unaware of. The more information you can provide to the healthcare professionals, the better they can treat the condition.

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Why we are on the subject, let us talk more about

You.

We do recognize how challenging your roles can be. But we know that the person with Parkinson's you look after will be okay if you are. So, your wellbeing should be top priority. You have a right to this wellbeing.

It is very difficult to get everything right. But if your intention is to do the best for them, then you *are* doing it right. It is normal to become angry/frustrated/tearful.

Speak to others and engage with support groups and services – you are not alone with your thoughts and feelings

Due to the nature of the condition and the slowness of progression and often subtle increases in the change in needs, you may not be aware of the changes to your own routines and/or the impact on your wellbeing. You may not realise that your hobbies, friends or even work are not receiving as much of your attention as before. It is important to try to maintain a healthy balance between your must do's and like to's.

Because of the unpredictable and fluctuating nature of Parkinson's, the effects of medication and varying duration of symptoms or immobility; it can be difficult to plan your day or your activities together as they may be too symptomatic to leave home, or you may be needed and not feel happy to leave them.

When possible, it may relieve pressure to loosen your planning. So instead of arranging to meet someone at say 10:00. Explain that you will *aim* to be there before 11:30 (for example). And do say that it will be dependent on things are on the day and you will call text if there are changes. This will help to alleviate the pressure of time constraints, increase understanding, and support, and minimize the need to rush – the stress of which can exacerbate symptoms and slow things further.

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Educate to avoid assumption.

People are more willing and more able to help if they understand your needs and a little more about the condition. Assumption is a destructive beast. Minimize the opportunity by affording people the opportunity to understand. Give them this leaflet? Anyone can talk to us if they want to know more about supporting someone living with this condition. We are always happy to increase knowledge, understanding and awareness.

Sometimes people who were close, will avoid you because they are frightened of saying or doing something that may hurt or upset you.

We do have a "Keeping in touch" contact card which may help you or the person you care for keep in touch with friends and family. Contact us for details.

When to help or assist.

Unfortunately, this is not straight forward – you probably know this already. As a general majority opinion, the most popular route is to say to the person that if they need help, to ask.

If, however they attempt a task that is risky or likely to cause distress, this maybe a time to be a little more insistent with your offer of help whilst reassuring them that next time they may be more successful.

There are those who will, and possibly always have taken all the help they can. We know that staying able and well for longer does require some effort and so for these individuals, a more assertive level of encouragement may be desirable.

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Find support for you.

When you have less time for yourself, friends, family, hobbies etc. then it is common to find that leaving the person you care for some own time can be more of a worry as they are out of sight but far from out of mind.

It gets easier with practice!

And putting as many safeguards in place as needed to quell your concerns and give yourself time to charge your batteries. This could be: -

- A simple phone call or checking in at arranged times
- A family/friend, befriender, Personal assistant, or carer to stay with them.
- Respite care if you need a longer break.
- A carers Assessment and/or support from a carers group
- Personal alarms – enablement through technology

What to do.

Tell your GP you care for someone. They should then register you as a carer and at least check on you and your role as a carer when you attend the surgery for other appointments.

Ask your council for a Carers assessment. They can provide information and assess your needs for respite/sitting services and you may also be able to receive a one-off annual payment of £200-£300 to treat yourself. Check if your local Carers organisation can do this with you (recommended if available) as they may often have more support that you may be unaware of such as Carer's Emergency cards and Contingency planning. All can help with easing the worry of the "what if's".

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Guilt

You should not feel guilty when you get frustrated angry or get things wrong. You have stayed with this person to look after them and those genuine intentions are everything. Your selflessness should never be allowed to be undermined when things do not go well or you experience carers stress – and carers stress is normal, and should be seen as a sign that its time for you to look at your needs.

Sleep.

Parkinson's can change sleeping patterns and behaviors. Commonly, vivid dreams can cause someone to shout and act out during the night, or wake up disorientated/confused. Others simply struggle to sleep or get comfortable and this can be exacerbated when a person needs to sleep during the day because of tiredness or fatigue or occasionally cannot avoid sleep which can be after medications.

It should be said that there are also some I meet sleep better than before they had Parkinson's.

The quality of sleep can impact considerably on physical wellbeing and mood. Often however, it is easier for the person with Parkinson's to sleep during the day than it is for the spouse/carer.

So, it is paramount that all options are considered to ensure that you have a restful a night as can be expected.

The most common and effective change I have seen is simply sleeping separately. Some feel mortified by this suggestion but it does not mean you cannot be together at all, but at the point when you need to sleep, you take to your own bed.

Do speak to us or a health care professional about aids, adaptations, and possible solutions for ensuring safety and overcoming comfort/turning/toileting issues that may help you to feel relaxed and sleep

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better. Relationships are much less likely to experience strain when both are rested.

Benefits.

Ensure you, and the person you care for, is receiving any entitlements. There are benefits that are not means tested so income and savings is not considered. If they receive non means tested benefits, then you may be able to claim Carers Allowance. You may also be entitled to a reduction in Council Tax. Use the benefit calculator at: -

<https://www.turn2us.org.uk/>

Other useful contacts: -

Carers Support Centre **Bristol/South Glos**

0117 9652200

Email carersline@carerssupportcentre.org.uk

The Carers Centre **BaNES**, Woodlands, Lower Bristol Road, Bath BA2 9ES

0800 0388 885

Email support@banescarerscentre.org.uk

Website: www.banescarerscentre.org.uk

North Somerset

Alliance Homes, 40 Martingale Way, Portishead. BS20 7AW

03000 120 120 opt5

<https://www.alliancehomes.org.uk/support-services/support-for-carers/>

The Almond Tree Foundation (**National**)

Online meeting and support

<https://www.thealmondtree.org/>

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Thank you for reading this.

This is a new evolving document. At [Face2face Parkinson's](#) we are driven by you, the experts and I have been asked to produce this.

I would like to make it as useful as possible and for this I need your help.

Please tell me what you would like to see more or less of; added or removed.

Either email me or contact me through our website, or post this page back to me, Kevin Carter with your thoughts. (address at bottom of each page)