



# Caring for someone with Parkinson's

Caring for someone with Parkinson's disease may be challenging, especially as the disease progresses. Aside from all the practical ways you can help, such as helping with medications, for example, you'll need to properly understand the disease and what your loved one is going through. It can feel overwhelming sometimes, but nonetheless, it's essential that you look after yourself as well.

Carers (or care partners) play very important roles in the lives of people diagnosed with Parkinson's disease. Care partners are often key players in the disease management process, therefore, the more knowledge and information you have about Parkinson's disease, its symptoms, treatment options, etc., the better equipped you will be to take on this role.

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## How to care for someone with Parkinson's disease

Your role as a care partner will take on different forms as time goes by. The extent to which you will be involved in caring for the person diagnosed will depend on how far the disease has progressed. Some care partner tasks include helping with medications, appointments and personal care as well as providing emotional support.

Taking on the role of a care partner is a huge responsibility, and it may not come naturally to everybody. Some people may find it more challenging than others, and that is OK. As this is a role many people may have to learn and adjust to, we have listed below different things you can do to make things easier.

### Learn about Parkinson's disease

Learning about Parkinson's disease will help you better understand and empathise with what your loved one (or the person with Parkinson's) is going through. It will also give you a clearer idea of what can be done for them, from [medical treatments](#) to [diet](#) changes and [regular exercise](#), so you can support



them in the best ways. It is important to know about the [myths and misconceptions](#) surrounding Parkinson's disease and to educate other people about these too. And, if you haven't already, check out our overview of Parkinson's disease and [living with Parkinson's disease](#).

Parkinson's disease is a complex condition, so even if the person you're caring for is able to go to their healthcare appointments alone, try to attend with them – it will help you understand their condition better. It is worth making a list of questions you want to ask and bringing it with you to the appointments. You'll find plenty of information throughout this site that can help you work out what you want to ask, including advice on being [newly diagnosed](#) with PD and our guide to available treatments.

## Find out what help they need

A movement disorder like Parkinson's can make simple tasks challenging. But pride, or embarrassment, may prevent people with Parkinson's (PwP) from asking for help. This is where you can step in, carefully. First, give them the chance and space to do tasks by themselves. If they're unable, then you can offer your help and assist; but do it calmly and with no fuss.

At times when you're both relaxed and calm, you could ask them about what tasks they might want help with (they may need help with bill paying or other paperwork, as well as tasks like cleaning, cooking and self-care). This approach gives them more control over the situation, and it could save them the stress of struggling to complete a task and then feeling like they've failed.

Equally though, don't offer to take on responsibilities that the person you're caring for is able to do themselves. Also, be honest about your own limitations. This way you can both agree on what you can help with and avoid any resentment.



It's very important to understand that people with Parkinson's communication and movement might get worse as the disease advances, so it's better to discuss how you plan to take care of your loved one ahead of time.

## Monitor their symptoms

Symptoms of Parkinson's disease change over time. It's important to look out for these changes in the person you're caring for, so any treatment they're receiving can be adapted, if necessary. Their care needs and lifestyle may also need to be reviewed. For example, there may be activities that, over time, may become unsafe for them to do, like driving.

In addition to looking out for changes in walking ability, speech and balance, keep an eye on your loved one's mood, sleep and behaviour. Unfortunately, mood disorders, including anxiety and depression, are common in PwPs. This can also take a toll on your own mental health. It is important to remember that symptoms like [anxiety and depression](#) (which cannot be "seen" are often more difficult to observe and understand in PwPs than physical symptoms such as tremor and rigidity. Finding the right way to manage their mental health, however, is just as important as getting the right treatment for physical symptoms.

## Get active together

Regular exercise is one of the most important things you can encourage a PwP to do. It can help relieve symptoms, improve movement ability (motor skills), strength, balance and memory and can help support mental wellbeing too. Try motivating your loved one to get moving by doing something together, such as taking a daily walk. Some exercises like dancing, Tai Chi and boxing have proven benefits. [Read more about how exercise can help.](#)



## Understand what your loved one is going through

Some Parkinson's symptoms may cause your loved one to feel self-conscious, embarrassed, frustrated and angry. Examples of such instances could include difficulty talking and expressing themselves, challenges putting on shoes and tying shoelaces, and spilling food/drinks while eating. In these situations, it is important that you find ways to reassure them and that you remain calm and patient. Your loved one needs to know that you understand that their struggles are as a result of their Parkinson's symptoms (and not because they are lazy or not putting in enough effort); and they need to be assured that you will patiently be by their side as they try to complete the task.

Parkinson's disease symptoms can vary from day to day, so your loved one's care needs can change all the time. This sometimes makes it hard to understand what they are going through. It can feel like they're being demanding if they need lots of support after being independent the previous day. But this is normal for Parkinson's disease.

## Strengthen your relationship

While Parkinson's can be difficult for both of you to deal with, it can bring you closer together. Build on this by doing enjoyable things together, however small, and making time to talk about things other than the disease. This will help both of you maintain a sense of your own identities and a feeling of normality in your lives.

Getting out can make living with Parkinson's less lonely for both of you. Involve other people too. The person you're caring for may feel reluctant to socialise because of their symptoms. But seeing family and friends can make them feel like they belong. Help your social circle [understand the symptoms of](#)



[Parkinson's](#) and that your loved one is still the same person. Reassure your loved one that their friends and family understand what they're going through.

## Communicate

As well as talking about topics other than Parkinson's, it can help to talk about what you're both experiencing so you feel less alone.

Listen to your loved one talk about their thoughts and feelings. Letting them express their feelings, and showing you understand, can help reduce depression and anxiety.

If their symptoms make speaking difficult, encourage conversation by asking questions that they can answer simply, such as yes/no questions or giving them a choice of answers. Repeat what you've understood back to them. You can also ask them to write things down if that's easier.

## Support for carers

Caring for your loved one isn't your only responsibility. It's just as important that you take care of yourself. As a caregiver you may feel guilty or selfish about looking after your own needs. But if you neglect yourself, you will be exhausted – and that isn't good for you or the person you're caring for. Remember, if you are not at your best (mentally and physically), you will not be able to fully give of yourself and provide the best care for your loved one. So, for your sake and theirs, you must make it a priority to also look after yourself. Listed below are some examples of how you can do just that.



## Look after your own health

Caregiving can feel overwhelming at times. If you feel like you can't cope, it's important to make an appointment with your healthcare provider, if that's available to you. They may be able to offer treatments that can help.

Don't put off seeing a healthcare professional for any physical illnesses either. And don't delay getting any tests you may need.

Share your problems with trusted family and friends to relieve some of your stress. And make sure you're getting enough sleep. Sleep is very important to your overall health, but your sleep may be impacted because of the strain brought on by caring for your loved one, and also because some of your loved one's symptoms might disturb you during the night. Make a conscious effort to rest when you can.

## Find a support group

A Parkinson's support group will give both you and your loved one a chance to talk to others in your situation.

Everyone's journey with Parkinson's disease is different. So, while it's important not to compare your experience, talking with other people can help you both feel less isolated. It will also help you share knowledge and encourage one another. You may find out about more resources, or different treatments, through your group. More experienced caregivers can give you advice on coping with what's ahead. Plus, you could both make friends for life.

Check out [support for people with Parkinson's in Africa](#).



## Form a care partner network

Don't be afraid to ask other family members or friends for help. You may not want to feel like you're burdening them but it's important that you have respite. And they may be more than happy to step in. It gives them the chance to understand what you're both experiencing.

If you can't find people to share the care, find out about possible respite or home help, even if you don't think it's essential right now. If things suddenly change, having a contingency plan in place means you'll have the support you need.

Check out [support for people with Parkinson's in Africa](#).

## Take time for yourself

Carry on doing all the things you love as much as you can. Don't feel guilty about finding time for friends, hobbies and activities that you enjoy. It's in the best interests of everyone. Caregiving is a huge responsibility and it can affect your mental and physical health. But maintaining your identity outside this role will make you happier and healthier, which will only be good for both you and your loved one.

## Sources (all accessed May 2022):

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