

information

COPING WITH DIAGNOSIS

Individual reactions to being diagnosed with Parkinson's are as varied as the symptoms of the condition. This extends to how each individual goes on to cope with the diagnosis and from that point onwards.

This information sheet explores the various responses that might be experienced when you or someone you know is diagnosed with Parkinson's. It also provides helpful advice for coping with diagnosis and moving forward.

Unfortunately, there is no "one-size fits all" or "best" way to deal with the changes and adjustments that come with living with a chronic condition. However, it is essential that the adjustment period, which will be different for everyone, is dealt with in as positive a way as possible.

Parkinson's Victoria recommends a proactive, practical approach, utilising credible, sensitive and appropriate information and support.

People may react in a number of different ways when adjusting to the news that they are living with Parkinson's.

Some people will want to learn as much as they can about the condition. Others will prefer to take in only what they need. Generally however, a person will experience a full range of emotions, filled with emotional ups and downs which last for varying lengths of time.

Upon initial diagnosis, it is normal to feel sad, angry, helpless, alone and scared which are all part of the natural "grief response". Give yourself, or your loved one, permission to experience these emotions.

Remember, it is likely that you have already experienced a number of life challenges, prior to being diagnosed with Parkinson's. Just as you coped with those new and difficult moments, you will also cope with life with Parkinson's. Find strength and reassurance in previous achievements, and reflect on those strategies which helped last time, such as talking with a friend or taking time out for "self-care".

The impact of diagnosis on partners, family and friends

A diagnosis of Parkinson's also impacts on the partner, family and friends of the one diagnosed. While they might not be the ones experiencing the physical and other symptoms related to the actual condition, they will also be "living with Parkinson's" as they share your journey through its various stages, and as they provide support along the way. Partners and family members will also experience their own unique emotions as they work towards acceptance. They may feel sad and helpless for someone they love who has been diagnosed, or scared about the future and the role that they will play. Partners, family and friends may even feel angry and resentful at times. These are natural reactions when experiencing a diagnosis of a chronic condition such as Parkinson's, and the sense of having lost control and not knowing what lies ahead or readjusting goals and dreams for the future.

It is important to give partners, family members and friends their own space to come to terms with the diagnosis, as they will also deal with the experience in their own unique way. Keep the dialogue open and talk with each other about the impact of the diagnosis.

For further information contact
Freecall 1800 644 189
www.parkinsonsvic.org.au

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Tips for coping with diagnosis

Maintaining Identity

Try not to define yourself by your illness. You are still the same person, with the addition that you are now managing a health condition as well. It is important not to lose focus of the other roles in your life that make you who you are. This may include being a husband/wife, parent, accountant, golfer, art enthusiast and/or community volunteer.

Be flexible

Parkinson's will require some changes be made to your overall lifestyle, perhaps hobbies or daily activities, but accepting these changes will be easier if you are flexible and adaptable.

Look for alternatives to any situation. For example: An activity such as camping in a tent, which may have been an outdoor activity you enjoyed, may no longer be appealing because of the increased challenges that your symptoms may create. You could modify your environment so that you are still able to enjoy trips away by choosing to sleep in a caravan or motel instead of a tent.

Always consider what options are available to you. You'll find that with an open and flexible mind there is usually a workable – and even enjoyable – solution.

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Disclosing your Parkinson's to others

When you feel comfortable, tell people that you have Parkinson's and what life is like now, living with symptoms.

Sharing with others relieves a huge burden, a feeling of having to “keep it all inside”, and you will find that those around you will appreciate your honesty. The more you speak about the diagnosis, the less daunting it becomes. With time, you will find that while Parkinson's is now a part of your life, it no longer dominates your thoughts.

You may also find that many people know little about the condition and how it can impact on an individual. This can make it especially worthwhile to share information about your experiences. You may decide to simply explain that you have a condition called Parkinson's and while it can affect your ability to move freely, it won't affect your mind and decision making.

(Parkinson's Victoria has a number of easy to understand resources that outline the condition and the types of symptoms that can be experienced which may be helpful in informing others.)

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Seek Support

Don't be afraid to ask for help. Family and friends will want to help but may not know how to go about it. They will appreciate knowing what they can do to provide support.

Professional support can also make a positive difference. You may find you suddenly have a lot of thoughts going through your head that you can't make sense of. Many people will seek the professional help of a counsellor to assist them in coping with their diagnosis.

A counsellor has expertise in helping a person to work through their thoughts in a constructive way. Often, individuals find talking with a counsellor provides an opportunity to talk openly without fear of offending or emotionally burdening a loved one.

There are also various groups around Victoria offering peer support for people living with Parkinson's. Consider contacting Parkinson's Victoria to find out about peer groups in your area. They are a great way for people living with Parkinson's to share their experiences with each other.

Maintain a sense of humour

Living with Parkinson's is going to be frustrating and even stressful at times. Try not to forget your sense of humour when things don't go to plan. Ensure you find time to have fun, catch up with friends and laugh.

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The importance of outlook

A positive and healthy attitude is vital to ensuring your quality of life is maintained and maximized. We encourage you not to withdraw from activities you really enjoy, but continue to participate in social circles and clubs to which you belong.

Stay active, eat well, and laugh when you can. These will ensure that Parkinson's doesn't consume your life and will put you in the best possible position to start and continue the journey that lies ahead.

Remember that Parkinson's Victoria is your peak-body for credible, relevant and up-to-date information and support. You are welcome to call our Health Team to discuss any questions, or talk through any concerns that you, a family member or friend might have in relation to Parkinson's. The Health Team can direct you to appropriate sources of support in response to specific needs and requests and across a broad range of topics.