

Just had a diagnosis of Parkinson's?

Everyone takes the diagnosis very differently, but it is not unusual to feel shocked, a little numb or it may be that you were expecting it. Some people can feel relieved as they knew something was wrong and now it has a name, they can begin to come to terms and deal with the diagnosis.

One thing is certain though that you have already probably been living with Parkinson's for many years, perhaps putting symptoms down to ageing, previous injury, other conditions or something else. As you learn more about the condition you may start to recall incidents from your past that may have been an early sign. It is not unusual for the onset of the condition to be 10 to 20 years before the symptoms become apparent enough to be diagnosed.

So let's look at some of the common questions we receive from people newly diagnosed:

Is it a terminal condition?

No.

Is it hereditary?

Generally no, although there is a rarer (about 5% of people with Parkinson's) form of Parkinson's that is familial when members from different generations of a family have had Parkinson's.

Do I have to stop driving?

No, unless you are told to do so or feel unsafe. Very few people are told to stop driving, most do not, and some stop of their own choice as should anyone who no longer feels safe to drive.

You must however, contact the DVLA to let them know of your diagnosis. You will normally be put on a 1-3 year renewal and need to complete a special DVLA form for Parkinson's. I suggest contacting your motor insurer/s although they often will tend to seem disinterested and there should be no change to your premiums.

Will I get dementia?

It is common to experience some cognitive slowing and this is often exhibited as difficulty word finding or losing your thread. This should not be confused with dementia, There is a slight increase in cases of dementia in people with Parkinson's, but it should not be expected.

Can I catch it?

No, that is one of the reasons why nowadays it is rarely referred to as Parkinson's Disease as this causes misunderstanding but just as Parkinson's.

What can I do to stay as well as possible?

I have supported people living with Parkinson's for over 13 years. The people I see who stay

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active; socially, physically, and mentally, remain much better for much longer, tend to be happier, take less medication and generally live more fulfilling lives. Exercise groups meet social needs as well as physical! It's what we all should be doing anyway but it is especially important for those with Parkinson's.

There is a big and active community of people living with Parkinson's and so many things you can try. They are happy places to be and you will take something along that is unique and will help others as well as feeling supported yourself.

PTO

So what's stopping you? Probably this - ANXIETY

This is by far the most common symptom I have seen in people with Parkinson's. Although we tend to view Parkinson's as a movement control disorder due to a reduced provision of the chemical dopamine in the brain; it is important to recognise 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 your mood will be lower too. This often manifests itself in the form of anxiety, apprehension, and you could find yourself dwelling on minor worries, making mountains out of molehills and may even experience 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 then it isn't them after all; they can stop persecuting themselves for feeling low or unenthusiastic now they understand the likely cause.

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

So you may learn that there is a group, exercise class, coffee morning etc that seems perfect for you. But watch out for the Parkinson's anxiety that will probably provide you with a whole myriad of reasons not to go by the time the event comes around, only to make you feel worse after when you think "I wish I had gone and given it a try"

So the moral of the story is: Do not let Parkinson's define who you are. Give anything a try, your presence will be very welcome, and if it's not for you, then try something else. By attending any of these groups you commit to nothing. You may come or go as you please, and most events are free or of little cost. Don't forget just by turning up, you help others.

For friends, family, spouses, and people living with someone who has Parkinson's.

This is a quirky condition, variable from day to day and moment to moment. No two people are the same, so it is unreliable to compare people you know or have known who have the condition.

Some of the symptoms and behaviours are difficult to understand, especially when someone is very capable and willing one day and maybe less so the next. It is easy to misconstrue these changes as being a sign of reluctance. "You did it yesterday, so why not today?"

The Parkinson's mind may make someone think they are performing actions as they always have, and when they believe they have lifted their foot 8 inches to clear a step, its

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only when they catch their foot after raising it only 6 inches they realise there is a problem. This can apply to speech as well, the voice can become softer, but they will feel as if they are talking as loud as ever.

It is good to be aware this as it can be frustrating to an observer and this can sometimes cause some friction in relationships. Someone with Parkinson's will normally be able to "instruct" muscles and limbs to perform bigger movements or to speak louder, however autonomy of movement (or the auto pilot) causes a reduction in the range of movement. Letting someone with Parkinson's know if they are not lifting their feet may help prevent an accident; or if they are speaking particularly quietly, but to do this whilst being mindful that they may have been unaware.

All groups and events are as open to people living with Parkinson's, friends, family, and anyone with an interest in the condition, as they are to people with Parkinson's.

Some other snippets and facts

Do try not be frightened by the amount of information and symptoms, **no-one gets them all.**

Parkinson's can affect anyone from any age, gender, ethnicity, rich or poor.

Everyone is different that's why there is so much information. A good example of this is that almost a third of people with Parkinson's never have a tremor. Do stick to the well-known resources such as Parkinson's UK, the Cure Parkinson's Trust and Michael J Fox foundation. Avoid sites that promote fear and a product that "cures all ills" but is unproven.

Parkinson's management has come a long way and continues to evolve. Medication can manage the condition well, but combining a well-managed medication regime with an active lifestyle is most beneficial. It is also empowering as it gives the patient some control.

To Do

Gather your useful contacts including your Parkinson's Nurse Specialist **and use them!**

Inform the DVLA of your diagnosis

Tel:- **0300 790 6806**

DO NOT LET PARKINSON'S DEFINE WHO YOU ARE

Remember you are still you!

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November 2019