

## Understanding your patient with Parkinson's

This is a document created from my observations as a Parkinson's Support Worker for almost 18 years, and as a personal assistant for people living with Parkinson's, for the past 5 years. Information has been gathered from many sources, primarily from spouses, carers, friends, and family and health care professionals.

So, let us begin by looking at Parkinson's, some of its more unusual symptoms. I hope this will help with understanding some behaviors and really help us to connect with patients, their family, and carers.

### **If you read nothing else, please do read this:**

People with Parkinson's are often at their best at appointments. I am unsure why this is but it could be that anxiety drives them to allow more time to get ready, take medication in a timely fashion; I am not sure, but it can drive the spouses to despair when there have been having difficulties for weeks/months but they appear much better on the day and say they are fine to the healthcare professional at the appointment.

This also causes us problems with benefits assessments or assessments for Blue Badges (Disabled Parking Badge).

Please do read further on under **Anxiety** and **Who is the Expert** for more information

### **Common problems to be aware of**

#### **The Basics**

- Parkinson's is a progressive and degenerative condition with no known cure.
- There are over 40 different symptoms – no one gets them all
- About a third of people *never* get a tremor or shake
- The most common symptoms I see is anxiety, apprehension, apathy, low mood or even depression.
- Medication can only mask the symptoms, and its effects are variable and often unpredictable.
- Every muscle in the body can be affected.

No two people with Parkinson's are the same. So, the following is intended to help understand symptoms and their impact on daily living and not a comprehensive list of what to expect. It would be generally expected to see these more of these symptoms and issues associated with them as the condition progresses.

A softening of the voice, slurring or hoarseness is common, as are reduced gestures, tone of voice, facial expressions, and body language – all of these are 83% of how we communicate the other 17% are the words. So, it is easy for someone with Parkinson's to be misconstrued or misunderstood. Wordfinding and losing one's thread midsentence can also hamper communication as can the use of computers and mobiles due to tremor and reduced dexterity.

People with Parkinson's should be afforded more time to allow them to express themselves as Initiating speech can be difficult or delayed. It is their body not their mind that is affected although there can be a cognitive slowing.

One should not judge them or try to finish sentences on their behalf.

With Parkinson's, a person often must focus on one task to do it well, and this can be walking.

Do not expect someone with Parkinson's to multi task. Do not overload them with instructions in one sitting.

It is beneficial to appreciate that although you may see someone with less expression, taking smaller steps, with altered posture, quieter voice, shuffling, dragging feet etc. To the person with Parkinson's, it often feels as their actions are the same as they have always been.

The variability in mobility can vary dramatically in minutes, from one day to the next and everything in between. This can be normal fluctuations in the condition and effects of medication; but also, can be exacerbated greatly by

- Stress
- Hot/cold temperatures
- Infections (e.g. a common cold which can come and go in a week, can affect symptoms for many weeks in someone with Parkinsons.)
- How long the person has had the condition (bear in mind that the onset of Parkinson's can be 5-20 years before any symptoms appear.)

Other Common symptoms to be aware of;

- Poor dexterity and co-ordination
- Pain
- Poor or no sense of smell
- Stiffness and rigidity of muscles and joints. There will be a need to both move around often and to rest often due to....
- Fatigue – A person must work and concentrate much harder to initiate actions. I have heard people describe having Parkinson's as "like walking through treacle"

### **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.

### **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 impact of Parkinson's anxiety.***

The person with the condition may learn that there is a group, exercise class, coffee morning etc. that seems perfect for them. But the Parkinson's anxiety 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 raining .....and 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. We know that staying active both socially and physically, is enormously beneficial. So, the anxiety can be an obstacle to them staying well and managing their own condition.

### **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 end 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. All the logical steps and considerations have gone and this may even include using walking aids.

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. Although this may be through no thought of their own, it may not seem this way; raising the risk of tensions, stress, and conflict.

Because of the reduced ability to sequence, analyze, etc.; we do hear of spouses/careers receiving less in the way of feedback, gratitude, appreciation, empathy, affection. It is very difficult for someone to give so much without having receiving the recognition/appreciation to keep them motivated and feeling valued.

### **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?**

This is often a combination of the person with Parkinson's and their spouse or carer. The fuller the picture they can give you, the better chance you have of treating their Parkinson's effectively. There is often a different perspective of the condition from the carer and the

person with Parkinson's. So do watch for the spouses/carers reaction when they say "I'm Fine" it is possible they have had a torrid time for months.

### **Difficulty absorbing long complex information**

Have you noticed how brief our documents for people who have Parkinson's are? It is very common, even in quite early stages of Parkinson's to have difficulty concentrating, or taking in and retaining information. Often people lose their enjoyment of reading or ask someone to verify their understanding of (for example) medical notes. That is why we keep our information concise but with the offer of finding out more if desired. The exceptions are this leaflet and the one for carers/family/spouses.

### **Further reading, information, and support**

I work at the Brain Centre on most Mondays/Tuesdays and Thursdays and can often be seen without an appointment. Please do pop in or contact me if I can help you with anything.

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