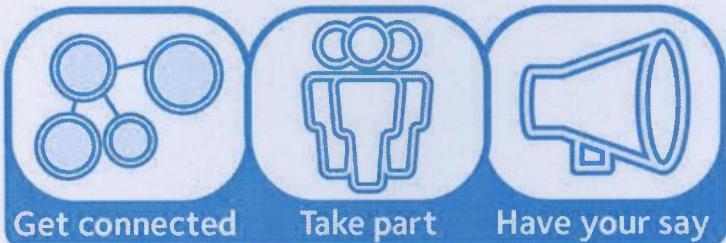


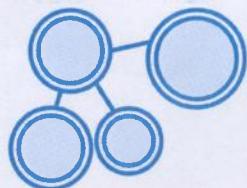
**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.



## June 2018 Research Roundup

Our Research Support Network (RSN) connects you to Parkinson's research. From finding out more about research to getting involved, there's something for everyone.

Here's our June Research Roundup with the latest research news and opportunities for you.



## GET CONNECTED

### Anxiety and Parkinson's: ask the expert

7 May 2018

As well as movement symptoms, people with Parkinson's may also experience other symptoms, such as anxiety. In this blog we explore the research into this challenging symptom.

Anxiety is a feeling of unease, worry, fear or dread, although it can feel different for everyone. Anxiety also has physical symptoms, which can include sweating, heart palpitations, breathlessness, dizziness, indigestion and nausea. Sometimes, people experience symptoms of depression as well as those of anxiety.

Everyone feels anxious occasionally, and different situations—perhaps a trip to the dentist or a flight—will cause different people to feel anxious. For most people, these anxious moments are few and far between and are over quite quickly. For someone who struggles with anxiety, these feelings can happen more often, last longer, and feel more intense.



Richard

I feel anxious when I'm stuck in traffic and think I'm going to miss my train

I feel anxious when I'm in a crowded place and feel like everyone is looking at me

I feel anxious when I've left the house and can't remember whether I locked the door or not

Anxiety is a normal response when we find ourselves in a threatening or dangerous situation. It exists to help us fight an enemy or flee from danger. A surge of adrenaline makes our hearts beat faster, our breathing deeper and blood rush to our muscles—preparing us to deal with a stressful situation. Now that we (hopefully) do less fighting and running from danger, this response can be activated inappropriately.

Whilst anyone can experience anxiety, it is estimated that at any given time, around 31% of people with Parkinson's will have significant symptoms of anxiety.

*"I'm having really bad anxiety and panic attacks. Feel as though my world is shrinking and am becoming housebound."* Parkinson's UK Forum User

Certain factors make it more likely that someone with Parkinson's will experience anxiety. Having more severe Parkinson's symptoms, as well as being diagnosed with Parkinson's at a younger age, are both linked with an increased likelihood of experiencing anxiety. Some symptoms such as problems with posture, stability, walking and freezing are also linked to anxiety. Higher doses of levodopa are not related to increased risk of anxiety, however people who experience dyskinesia or fluctuations in the effectiveness of their Parkinson's drugs are more likely to have anxiety.

We're joined by Professor Richard Brown, Professor of Neuropsychology and Clinical Neuroscience at King's College London.

### **What is the connection between Parkinson's and anxiety?**

"Anxiety, like all behaviour and emotion, is ultimately controlled by our brain. Anxiety is related to a complex set of brain areas and chemicals, many of which are affected in Parkinson's. However, there is little evidence that dopamine is involved in anxiety. This means that dopamine medication tends to have little effect on whether a person feels anxious or not.

People with Parkinson's seem more prone to anxiety than people without. Some of this will be down to brain chemicals. However, some of it will be down to how anxiety and Parkinson's interact. When stressed and anxious the symptoms of Parkinson's tend to get worse because of wide-spread effects on different systems in the brain. This in turn can make someone feel even more anxious, and so on, in a vicious circle."



### **Are existing treatments for anxiety helpful for people with Parkinson's?**

"Anxiety (and depression) are routinely treated with a class of drug called Serotonin Reuptake Inhibitors (SSRIs). Medication can certainly be useful to help manage anxiety and depression. However, no clinical trial has confirmed this in Parkinson's. We do know, from the use of SSRIs more generally, that many people fail to respond to such medication, or need to stay on it for long periods of time to maintain any clinical benefit. Even then, people often report persistent lower levels, but still unpleasant, anxiety even when on medication.

Psychological treatments, especially Cognitive Behaviour Therapy (CBT), have been specifically developed to treat anxiety in its different forms, and can be highly effective. Unfortunately, as with medication, we do not have any formal scientific evidence to demonstrate exactly how well it works in Parkinson's and for whom. Despite this, CBT for anxiety is the recommended treatment for anyone experiencing problems."

### **Do you know of any coping mechanisms that people with anxiety find helpful?**

"The problem with anxiety is that short-term coping strategies may make the problem worse in the long-term. If something is making us anxious, the simplest and quickest way to reduce the anxiety is to 'run away' or avoid the situation in the first place. Not surprisingly we learn that such behaviour reduces our anxiety so we are more likely to do it in the future. This is fine if we are avoiding a dangerous situation, like walking through a field with a bull in it. However, these strategies are less useful if we are avoiding going to the supermarket, eating in a restaurant or even walking to the front gate. Avoidance leads to us stopping doing things, or means we are even more anxious when we have to do them.

A helpful strategy is to continue doing things that make us anxious, but in a way that allows us to feel in control. Relaxation and breathing exercises can help reduce some of the physical symptoms of anxiety and prevent them making the motor symptoms of Parkinson's worse. There are also simple techniques to help manage worry, such as making a note of the worries and coming back to them later, rather than letting them go round and round in your head.

So, doing less of the unhelpful coping strategies such as avoidance and worry, and more of the helpful things such as controlled exposure to the things that make us anxious, relaxation and breathing exercise, and worry management.

Self-management can be very helpful, but anyone with problematic anxiety should seek professional help. Your GP can advise on what services are available locally or you can refer yourself to your local NHS 'Increasing Access to Psychological Therapies' (IAPT) service."

### **Are some people more prone to anxiety than others?**

"Some people are more prone to problematic anxiety than others—it can be a feature of our personality. Higher levels of anxiety also have a strong genetic component. This means that if our parents were anxious, we are more likely to grow up being anxious ourselves. Also, situations that drive our anxiety can be learned. If we grow up with someone who is anxious about lots of things, and tends to cope by avoidance and worry, we can learn these same traits."

### **Why is there a need for a new approach to managing anxiety?**

"One disadvantage of CBT is that it can be hard to access for some people and involves a considerable time commitment over a period of months. While not necessarily replacing CBT, we are looking for other simpler treatments that people may be able to use on their own via a computer, tablet or smart-phone, and that can be done over a period of weeks rather than months. Our current research is examining the potential of one such approach to see if it is worth developing further."

Parkinson's UK have awarded Richard and his team £44,196 to investigate interpretation bias and anxiety in people with Parkinson's.

Previous research has shown that people who are anxious have a tendency to interpret situations as more dangerous or threatening than they actually are. For example, imagine you see a friend across the street and they do not wave. An anxious person may worry that the friend is upset about something they did—a negative interpretation, rather than assuming the friend did not see them—a neutral interpretation. This 'negative interpretation bias' can trigger feelings of anxiety and, in this scenario, may cause the person to worry about the event or avoid the friend.

### **How will you test whether people with Parkinson's have this tendency?**

"We will use a range of approaches. For example, we will present people with different hypothetical scenarios that can be interpreted in more than one way—specifically a negative (or anxious) way or a positive or neutral way. We expect that anxious people are more likely to draw a negative interpretation from such ambiguous situations. This is 'interpretation bias'. We believe that this automatic negative bias serves to strengthen and maintain anxiety.

Previous studies have shown that people can be trained to make more positive or neutral interpretations and thereby feel less anxious. If we find that anxious people with Parkinson's have this interpretation bias, we will then test to see if a computer-based training is beneficial."

## **What will this training involve?**

"We will use simple techniques that prompt or guide people away from the negative interpretation to the more positive or neutral one. We hope that doing this repeatedly, reduces the strength of the natural negative bias, and so helps to reduce the anxiety over time."

## **What are you hoping to find?**

"Having zero anxiety would not be good for us. Fear has evolved to keep us safe from real danger. A person with no fear (and no sense!) would not survive very long. However, no drug and no psychological treatment makes a person 'fearless'. We are just aiming to 'turn down' the level so it stops being unpleasant and problematic."

If you're experiencing anxiety you should speak to your GP about local support. Always consult a qualified health professional or specialist before making any changes to treatment or lifestyle.

Huge thanks to Professor Richard Brown, Professor of Clinical Psychology at King's College London.



## **TAKE PART**

## **Rapsodi – Identifying early features of Parkinson's and Gaucher**

Professor Tony Schapira and the research team across the UK have launched a pioneering online research study. The aim is to understand how subtle changes occur prior to the onset of motor symptoms in Parkinson's.

One barrier for developing better treatments and a cure for Parkinson's is that by the time movement symptoms appear, 50% of the dopamine-producing nerve cells have already been lost.



### **What's involved?**

Filling in an online questionnaire, that should take no more than an hour to complete, and receiving yearly emails collecting further information. The team will also be asking you to provide saliva samples in a kit that will be posted to you, with a prepaid return envelope.

For more information visit the study website ([rapsodistudy.com](http://rapsodistudy.com)).

### **Who do the researchers need?**

800 people with Parkinson's or Gaucher and family members of people with either condition.

### **Interested in taking part?**

Please register your interest on the website ([www.rapsodistudy.com](http://www.rapsodistudy.com)).

If you have any problems accessing the questionnaire, please contact Soraya Rahall by email ([s.rahall@ucl.ac.uk](mailto:s.rahall@ucl.ac.uk)) or phone (020 7794 0500 ext. 31588).



## HAVE YOUR SAY

### Involvement: An inside story

At Parkinson's UK, we believe that involvement is key to ensuring that research meets the needs of those affected by Parkinson's. As experts in the condition, it makes sense to bring people affected by Parkinson's and researchers together to develop research projects. Here's the inside story about why this work is so valuable: <https://bit.ly/2JCfp8z>

### A message from Liz, our new Research Support Network Manager

Hello everyone, it's a pleasure to be here at Parkinson's UK!



In this role I'll be leading the growth and development of the Network, to enable and encourage more people to get involved in research to deliver better treatments and a cure for Parkinson's.

I have a background in Volunteer Management, most recently at Breast Cancer Haven and Battersea Dogs and Cats Home. I look forward to learning about Parkinson's research, and the ways you all engage with it.

In the past two years, the Research Support Network has grown steadily, and there are now more opportunities than ever to Take Part and Have Your Say. I'm excited to take on the challenge of working with all of you to ensure that everyone with an interest can engage with research in a meaningful way.

And finally, as it's National Volunteers' Week, thank you for all you do to support the work of Parkinson's UK!

I look forward to meeting and working with lots of you in the future. Please get in touch anytime!

Liz Nash

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Thank you for supporting research!

Best wishes

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