Learning from Lived Experience

This presentation was delivered by Sally Bromley, chair of the Oxford Branch of Parkinson's UK, at a conference in London, England on 16th March 2018.

The main focus of the conference was the implementation of guidance recently updated by the National Institute for Clinical Excellence.

Abstract of the talk

Living with a chronic degenerating condition is hard. From the moment of diagnosis to wherever the Parkinson's has taken you it is relentless and unpredictable, but Sally has found that by keeping active and by helping others she feels better herself.

The talk will share Sally's own experience of living with Parkinson's and the patient journey from pre diagnosis, and will also consider patients' varying responses to their condition and its treatment.

Based on her extensive work with fellow people with Parkinson's (PwP) Sally co-authored the First Steps course for newly diagnosed PwP. This initiative has been funded by Parkinson's UK. She will report on the impact of this course on those who have attended it and the PwP who present it.

First Steps is a good example of a successful initiative predominantly undertaken by PwP themselves, with minimal support from health care professionals. Sally will argue that this energy, enthusiasm and commitment can best be exploited in the context of creative collaboration between patients and professionals. She will provide examples of this from the work of her own Oxford Branch in the areas of research, exercise and physiotherapy, clinical practice, and other therapies and activities such as Dance for Parkinson's. It is not obvious that the NICE guidelines give sufficient importance to this kind of interaction.

This talk aims to give delegates a deeper and more personal understanding of what life with Parkinson's is like, and the positive steps that many PwPs already take to mitigate its effects. It challenges the traditional relationship between health care practitioners and PwP, and suggests that an engaged partnership can yield major benefits for all involved. Parkinson's is a complicated and multi-faceted condition and needs creative, diverse initiatives to enable patients to take control of the condition and to provide them with the best possible quality of life.

Slides and transcript

On the following pages you will find copies of the slides used in the presentation, alongside a transcript of Sally's talk.

For more details…

Videos used in the presentation, along with many other resources and links, can be found at

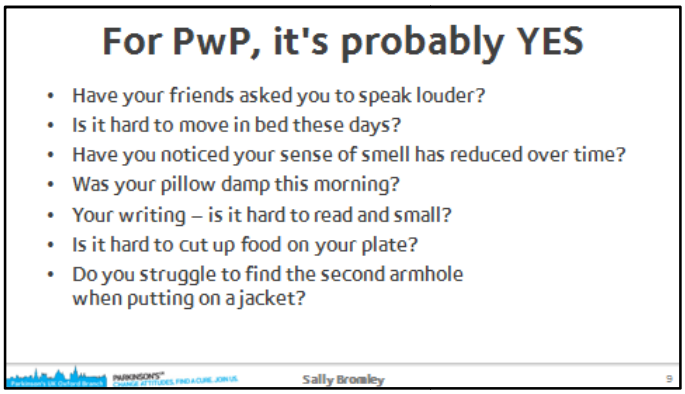
https://oxfordparkinsons.org.uk/hcuk2018

Learning from lived experience

Good morning. I'm going to start by asking you some questions.

For PwP, it's probably YES

If you have Parkinson's, your answer is probably YES.



When you visit the neurologist these questions are never asked. Instead we are diagnosed by examining our movement, through watching our walking and balance; our ability to open and close our fingers. Yet for most of us living with Parkinson's, it is our reduced ability to 'do stuff' that irritates. Peeling vegetables for example... the peeling bit is not too bad, but turning the veg in the other hand is hard.

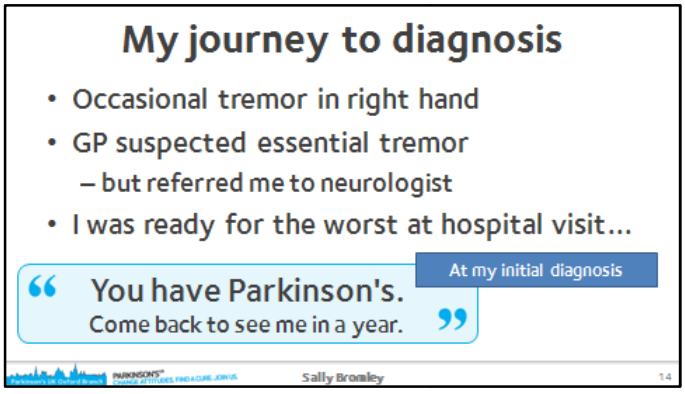
Trying to read a shopping list when your writing is about as big as microfiche and looks like a spider has wandered aimlessly across the paper is horrid.

Waking up with a damp pillow because we may have excess saliva makes you unhappy.

Not all of us have the same symptoms. Each one is not a major problem but collectively they are a nuisance, and can compound to make you feel as if you have lost control of your own body.

My journey to diagnosis

I'm going to tell you my Parkinson's story today. My story is not the same as anybody else's as we are all different. Yes we all get progressively worse but we each have different aspects or symptoms of Parkinson's.



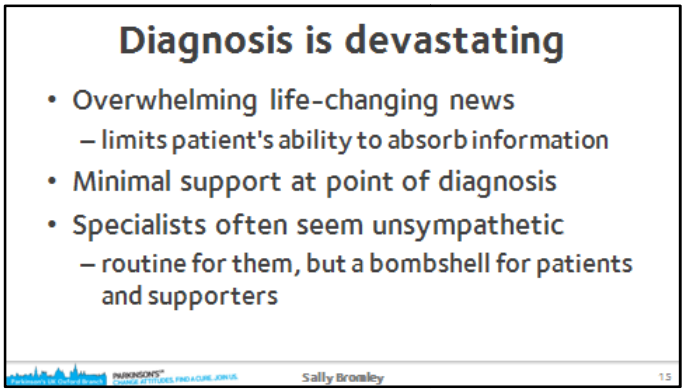
Today I am pleased to be here, telling my story early in the day. I'm usually the last to speak and this is a pity as the person living with this horrible condition provides the context for the rest of the day.

Let's start at the beginning. I had been aware that my right hand had a tremor at times. I thought I was resting my wrist at an odd angle but it gradually dawned on me that perhaps I should see my GP. She looked at me, and moved my wrist and arm about and reported that though she believed it was almost certainly essential tremor, I ought to see a neurologist.

I had convinced myself that I had got Parkinson's by the time I visited the hospital. I was ready for the worst, or so I thought, but those three words – You have Parkinson's – are etched on my brain. Nothing could have prepared me for the bombshell of hearing those three words.

Diagnosis is devastating

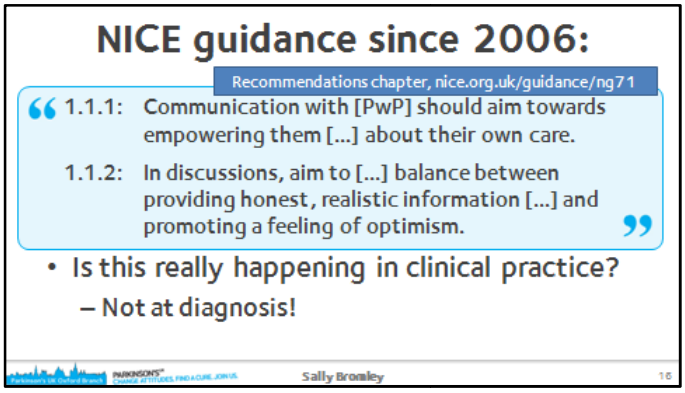
You go to see a neurologist who tells you you have Parkinson's, and that's it? So devastating is the news that most people hear very little else of the 10-minute consultation. At this stage there's little a neurologist can do except offer some literature. This is a typical diagnosis. And this must change.



I have heard many stories of the seemingly unsympathetic clinician who dishes out horrible news to unsuspecting people, at times not even looking at them, and closing the appointment with the words, 'I'll see you in year'.

NICE guidance since 2006:

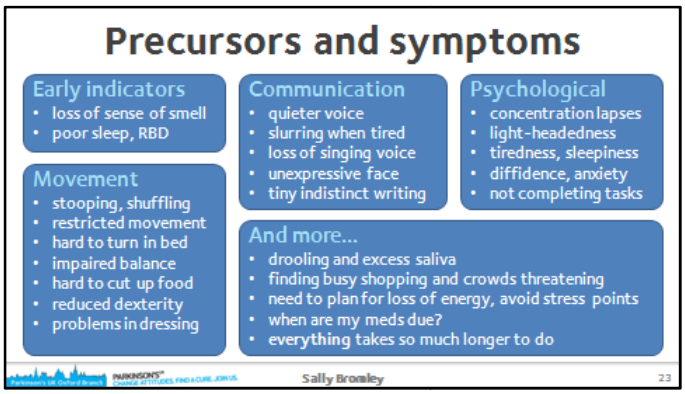
The NICE guidance says very little about the patient's experience of diagnosis (though it's very clear and sensitive on palliative and end-of-life care, by contrast).



These recommendations are pretty much the only material that's directly relevant. They haven't changed since 2006, but our anecdotal experience is that even this minimal expectation is far from being met for patients going through the life-changing event of diagnosis.

Precursors and symptoms

OK, so now I've got Parkinson's. What does that mean in real life?



Early indicators

- losing my sense of smell – many people are affected, usually about 8-10 years before diagnosis
- disturbed sleep – I shout and scream and lash out. This started a couple of years before diagnosis, and I once bit my daughter who was worried about my shouting in my sleep. This is called REM sleep behaviour disorder and is being seen as a strong predictor of Parkinson's.

Movement

- a slightly stooping gait
- walking with my right foot slightly dragging
- not swinging my right arm when I walk
- difficulty turning over in bed, more like a beached whale
- losing my balance
- finding it hard to cut food up
- I ask the cashier to pack my bag at the checkout as I'm so slow
- I can no longer play the piano due to reduced dexterity
- finding it increasingly difficult to dress – fiddly buttons,, zips etc and everything getting stuck!
- unable to find the second armhole in jackets, coats and cardigans

Communication

- voice changes – mine is quieter, I stutter at times and my speech can be slurred, especially towards the end of the day
- I've lost my singing voice – a great personal loss
- having a blank face at times – this is called the mask. it makes it hard for people to have any idea of how I'm feeling.
- my handwriting is impossible to read – it is small, indistinct and wavers about on the page
- Psychological
- forgetting your train of thought
- feeling light headed
- tiredness, and falling asleep
- losing my confidence
- suffering anxiety – this is a major problem for many of us
- not always finishing a task, abandoning jobs, leaving doors and drawers open

And more…

- excessive saliva causes dribbling and drooling – is your pillow damp in the morning?
- I avoid crowds as I find them threatening, so I shop at quieter times.

- Clothes shopping again done at quiet times. Having to ask for a seat in the changing room leaving little space to try clothes on, means I usually take clothes home to try on, as the process of dressing also takes my energy.
- Constant planning – how will I get there? Will my energy run out? When is my medication due?
- everything, but **everything** taking much longer to do

Just 24 examples there and I probably could think of more.

Many people suffer mood changes so overwhelming that they are treated for depression.

This patient, other patients

I've heard from many people since my diagnosis nearly ten years ago, and I recognise that we react differently. Some tell no-one, some tell their nearest and dearest, and others tell everyone. But few actually seek support – often because they don't want to see their future in others with more advanced Parkinson's. For some it's not until they meet a specialist Parkinson's Nurse that they even find out about organisations and opportunities specifically for people with Parkinson's (PwP).

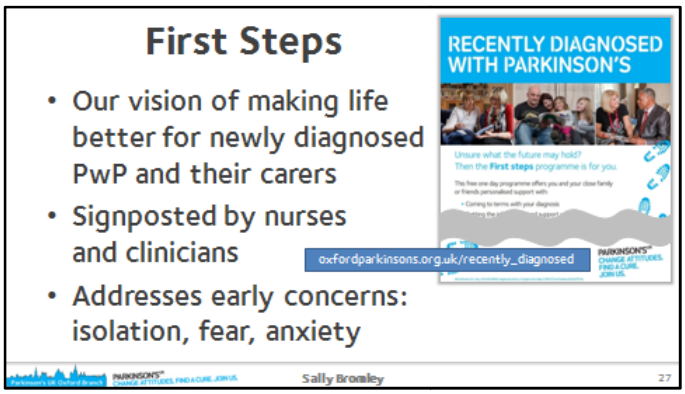
One of the first things I did was to take part in a charity event for Parkinson's UK. I thought hard about doing something I'd be unlikely to have done if I hadn't got Parkinson's. So I did a skydive, and fell out of a perfectly good aeroplane at 12,000 feet. It was the scariest yet most exhilarating thing I've ever done!

Over the first few years after diagnosis I became actively involved with our Parkinson's UK local Branch in Oxford. I got to know many PwPs and learnt about their experiences of diagnosis and beyond. From all this a strong message came through: PwPs sensed a void between diagnosis and eventually coming to terms with their condition. It was clear that PwPs wanted support and nurture through that process, and that most don't get it.

This required some creative thinking. The diagnosis is scary and we needed to come up with something to alleviate the anguish most of us experience. Before we knew it First Steps was born!

First Steps

Alex Reed has Parkinson's and he runs a Parkinson's therapy centre in Northern Italy. Supported by Parkinson's UK, I worked with him and other PwPs to create a two day small-group workshop in Oxfordshire for newly diagnosed and their carers. It aims to help them understand more about the condition and how to cope with it.



First Steps has been running for nearly 3 years and has received consistently excellent evaluation from participants.

Parkinson's specialist neurologist, Michele Hu says: "I have seen how much the patients have valued the programme with particular praise for the wealth of information shared in a relaxed, open atmosphere and the chance to meet with other people in a similar situation."

Participant experience

At a First Steps reunion event last October, we interviewed some participants about their experience of the workshop. Here are Ash and Laura. Ash was diagnosed at the young age of 35.

Participants reflect

Participants are guided towards seeing that their life may need to be reassessed and changes made. I asked Pam how she felt when arriving at the workshop.

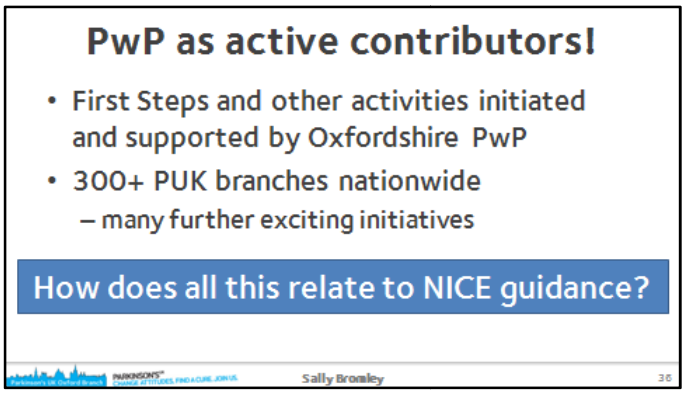
Making a difference for PwP

Today the programme has helped over 300 people affected by Parkinson's to come to terms with the diagnosis. It's planned to be rolled out to other locations nationwide, beginning with Plymouth, Aberdeen and Southampton. But I guess if any of you are still curious as to why it's successful.....?

The answer is Parkinson's. It was conceived by, written by, tested on, evaluated by, and most importantly, is presented by PwP. This is what gives the First Steps programme validity and credibility. This is, I believe, the recipe for its success!

PwP as active contributors!

I hope I've been able to paint a picture of PwP – especially in the first few years after diagnosis – as energetic, highly motivated, and determined to take control of their own futures. The feedback from First Steps participants, and other evidence, clearly shows that PwP greatly value such initiatives. I can only report on the work I know about in my region, but Parkinson's UK has a vast network of Branches across the country many of which are doing equally exciting work for the benefit of their members. [CLICK FOR MORE]



But we're here today to talk about implementing the NICE guidelines for Parkinson's. Is there a place for patient-led activities like this? I think we should be talking about that, and challenging whether the guidelines give it enough weight.

Story time!

When I was in Italy at Alex Reed's European Parkinson's Therapy Centre, we had a class called Breathing for Relaxation. The class began – join in – Breathe in… Breathe out... Breathe in... Breathe out... Breathe in – at the next "breathe out" the man at the other end of the table let out a very loud 'Errgghh'. He did it again. I was with a fellow parkie and we both started to giggle. This turned to laughter which in turn woke the man up. He smiled and said 'I was dreaming'... 'I was dreaming of cake'… 'I was dreaming of chocolate cake'. By this time we were all laughing. Then his wife suddenly put her head in her hands and sobbed. She

explained it was the first time she'd heard her husband laugh in over a year and hadn't even see him smile. How sad is that. I cannot imagine a day or even an hour when I don't smile or laugh.

PwP and health professionals

Since I have been Chair of the Oxford Branch I have nurtured relations with our local health professionals. I involve them in meetings, invite them to our activities, and ask them to inform the group about the work they do. This has led to a mutual respect and trust.

We now reserve our August meeting for members to discuss and share their concerns. Health professionals are invited to the follow-up meeting in September, where they can offer solutions and find out first hand what PwPs are concerned about.

My GP is also a GP lecturer and makes use of stories from my experience.

As an Expert Patient Tutor I attend sessions when Year 5 medical students examine me, ask me about my history and I offer information about living with PD. This way future GPs who have been through this initiative have a better understanding of Parkinson's.

Patient involvement in research

I'm lucky to live in Oxford which is a major research centre. Parkinson's UK has funded the Monument Research Project over ten years. This project has two strands: lab research into fundamental disease mechanisms and possible treatments, and a longitudinal study tracking over 1500 patients, siblings and controls. The University's School of Psychology has studies on depression, apathy, motivation and reward and many other psychological investigations. Oxford Brookes University has a Movement Science Group.

Many researchers from these groups have come to our Branch meetings, usually with about 80 members present, to give talks and to ask for research volunteers. They do this on the condition that they return with the results of their study!

Patients reach out

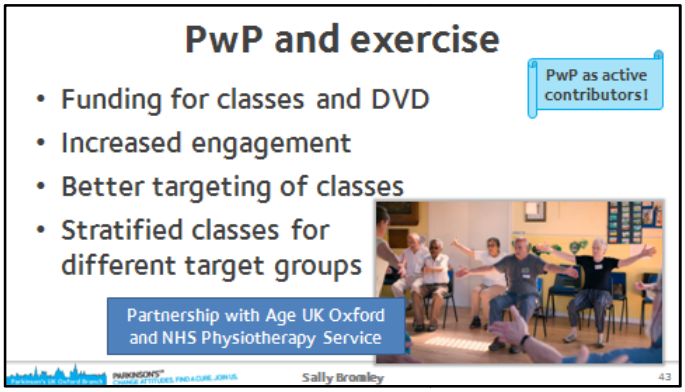
To date just in January I have taken part in projects looking at motivation and reward, decision making, and memory. The latter meant I have had to go into MEG and MRI scanners.

I give presentations to several groups, including 120 pharmacy students at Reading University, and hospital nurses at their PD Study Days twice a year.

I have spoken at the OPDC Research days, and at concerts and other events we put on.

Many members of my Oxford Branch are equally active, and I'm sure there are others across the country doing similar work.

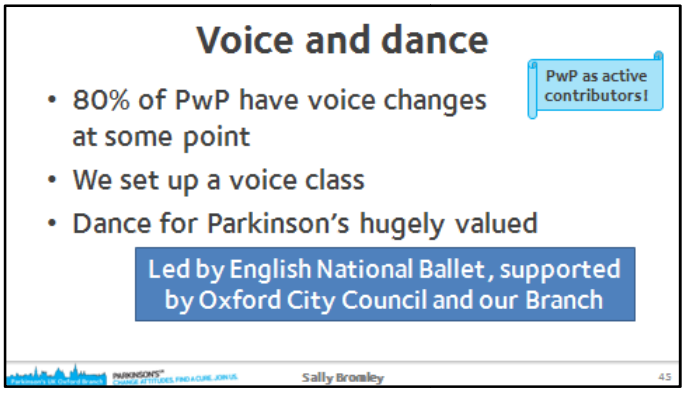
PwP and exercise



There's no doubt exercise is good for PwP. Many of our members benefit from a gentler alternative to the well-established commercial PD Attack and PD Warrior programmes. Our Branch has collaborated with Age UK Oxfordshire and the NHS Physiotherapy Service to offer and subsidise Big, Bold and Balance classes around the county. The Oxford class has around 36 regulars aged 67 to 92. It suits older people new to exercise and to those with more advanced Parkinson's. A DVD of the class makes it possible for people to continue the exercise at home.

Voice and dance

Our voice class 'Finding your Voice' is popular and we enjoy weekly voice exercise and singing, and even occasional public performance.



We also enjoy the Dance for Parkinson's classes brought to Oxford from English National Ballet. Like other classes there's a social element valued by all participants. This video clip was for ENB's Big Give project.

Partnership in action

A high point of all these collaborations was the patient-led conference that our Branch staged last year to mark the 200th anniversary of James Parkinson's seminal "Essay on the Shaking Palsy". Devised and led by PwP, it brought together…

- researchers from local academic institutions,
- nurses, physiotherapists and other practitioners,
- and people with Parkinson's talking about how they take control of the condition.

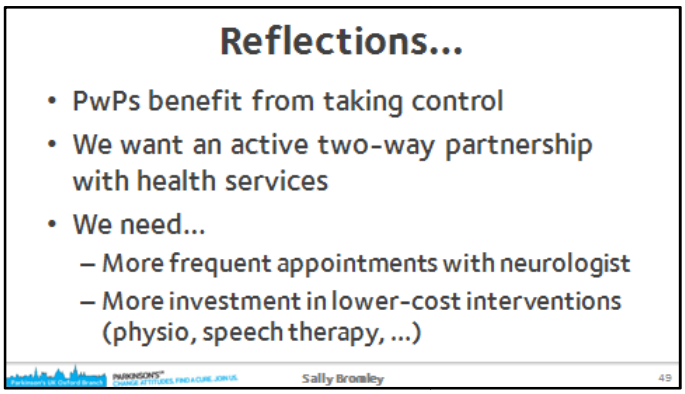
True partnership in action.

Reflections…

My final message:

PwP should do their best to take control of their Parkinson's. Central to this is PwP having a say about their treatment.

We want to know: why is one 10-minute appointment per year considered adequate?

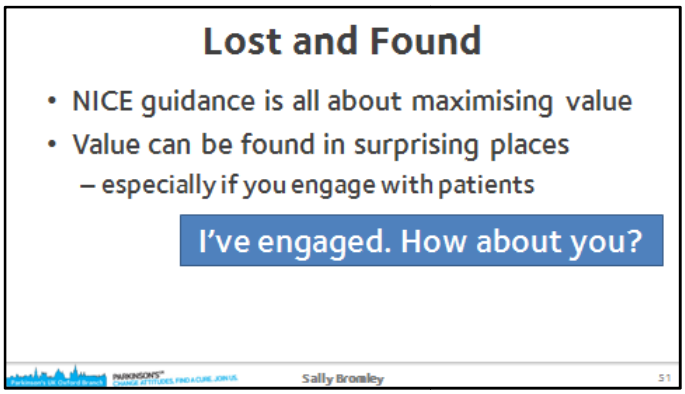


We want to know: why is it so hard to get specialist occupational therapy or speech therapy in some areas?

We are told **there is no money** and that we should do more with what we have, but in some areas we have nothing – and it's hard to do more with nothing.

Are we relying on the evidence of statistics and failing to see that behind every number is a real person living with a deteriorating chronic condition?

Lost and Found



I'm not one to hang on to things that I have no control over. Linda Ronstadt the singer lost her voice to Parkinson's and in a recent interview merely conveyed her irritation. For me, having sung in choirs most of my life, losing my singing voice has been a kind of bereavement. Losing my ability to play the piano, due to reduced dexterity, has had the same effect. But if I hang on to my regret, I will carry it around like baggage. I must let it go. I'd do anything to eradicate Parkinson's and I wish I didn't have it. I've lost a great deal yet discovered an inner strength.

And the Real Me??

I'm a wife, mother and grandmother. Though supported tremendously by my family I am conscious that as my body deteriorates as Parkinson's slowly and insidiously consumes me, my grandchildren will not remember a fine picture of me. Through it all, I have not lost my smile – yet – and I still have a sense of humour.

Thank you!

To sum up... Am I angry? No.

Frustrated – at times;

Regretful – not really;

Happy – of course;

And when I wake up each day, how do I feel?

Good!

Sally Bromley

Parkinson's UK Oxford Branch

16 March 2018