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Living with Parkinson's Disease
A new resource on healthtalkonline.org

The award winning website – **healthtalkonline.org** – is launching a new section with the voices of 45 people from many different backgrounds and from all over the UK who have been diagnosed with Parkinson's disease or who are caring for someone with the illness. Based on interviews carried out by the DIPEX Research Group at the University of Oxford and guided by an advisory panel of people with the illness, carers and health professionals, you can see, hear and read a wide range of experiences and perspectives on what it is like to have been diagnosed with Parkinson's disease. There are people who are young, older, some recently diagnosed and others more severely affected who may have lived with it for a long time.

'If people have never met you before, they'll probably think, "Oh Christ, he's drunk!"'

Many people diagnosed with Parkinson's disease may not only have to deal with the disease but also the sometimes unhelpful reactions of other people. Parkinson's disease affects approximately 120,000 individuals in the UK. Often, neither they nor their carers will have more than the vaguest of notions about what it is and why people get it. Perhaps even more difficult is that no-one can really tell them what their future lives are going to be like since each case of Parkinson's disease tends to be different. The popular image of a person with Parkinson's disease is that of an elderly person who has a tremor but one in twenty of those diagnosed will be under forty years of age. Although the key symptoms of Parkinson's disease are tremor, slowness of movement, rigidity and difficulty with balance, the illness affects people in many different ways and its impact on the individual can be very wide ranging, in terms of both function and emotional and social wellbeing.

People talk of how they have come to terms with the knowledge that, while they view themselves as being the same person they have always been, they cannot be because things like walking or brushing their teeth have become mysteriously difficult: *'I still know how to do things, but my body won't obey'* **Sharon**

They express their surprise at discovering that Parkinson's disease won't kill you and they talk of how they want others to view them: *'I don't want their pity. I want their understanding. I want them to realise what I'm going through'* **Natalia**

Then there are the issues for the carers of those with the disease: *'We knew that the standard medical advice is that, if someone can do something themselves, however slowly, they should and I mostly deliberately didn't help unless he asked. But looking back, I think we could have been cleverer about all that, especially when I now read in his diary how much he resented time wasted on doing trivial things slowly'* **Mari**

The interviews on **healthtalkonline.org** portray the diverse experiences of Parkinson's disease and include discussions about what it feels like to receive the diagnosis, the effects on employment, relationships, ways of negotiating life in a world that does not always understand what it is like to be them as well as the effects of different drug treatments and the newer surgical options.

'I can't explain the feeling that I felt but it was like being born again and it was really fantastic and, like when you always had the use of your legs, sometimes in life you

take it for granted that you can do the things that you can do, but when those things are taken away, it's a real reality check and it makes you appreciate just how lucky you are in what you've got in life' Stephen

To access the site, or to share your own personal health experience, go to:

www.healthtalkonline.org

ABOUT DIPEX

DIPEX, a registered charity no. 1087019, has created two websites – www.healthtalkonline.org and www.youthhealthtalk.org – of people's experiences of almost 50 different illnesses and health conditions. The websites are aimed patients, their carers, family and friends, doctors, nurses and other health professionals and are based on in-depth qualitative research carried out by the DIPEX Research Group at the University of Oxford.

Users of our websites will find accounts – presented through video, audio and written material – which resonate with their own perspectives and experiences of issues such as reaction to diagnosis, consultation with their doctor, effect on work, social life and relationships, decisions on treatment options and side-effects of treatments. The questions that patients want answered are identified in the interviews with patients and summarised on our websites.

To date, we have covered illnesses including cancer, heart disease, neurological conditions (Parkinson's, epilepsy and autism) chronic health issues (HIV, diabetes, rheumatoid arthritis) and mental health. We also provide experiences of women's health (pregnancy, breastfeeding, antenatal screening) and publish young people's experiences (including epilepsy, sexual health, teenage cancer) on our dedicated website – youthhealthtalk.org.

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