I have Parkinson's
What kind of disease is that?

- It is not infectious, does not usually run in families, and we don't know why people get it.
- But it makes me slow and stiff, and my hand may shake a lot.
- About one person in every 500 has Parkinson's. That makes about 120,000 people altogether in England, Wales, Scotland and Northern Ireland.

People with Parkinson’s do not have enough of a chemical called dopamine in their brain. The brain uses this to send messages to the muscles. Lack of it means people with Parkinson’s are often very slow as they move, are very stiff, and shake badly in one hand or other parts of their body. Some get quite a lot of pain, tingling or cramp.

Most people who get it are aged 50 or over, but some much younger people are hit by it.

Many people live with Parkinson’s for 20 years or more and manage to lead active and fulfilling lives.

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Edinburgh Branch of Parkinson’s UK. 0131 449 2705

Parkinson’s UK is the operating name of the Parkinson’s Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).

Free Helpline 0808 800 0303

www.edinburghparkinsons.org

I have Parkinson’s
I’m sorry I’m so slow!

- Parkinson’s makes me very stiff, slow and clumsy, and my hand may shake a lot.
- So things which other people can do quite quickly, like paying for their shopping or going to the toilet, can take me a very long time.
- I know it is annoying for you when I hold up the queue, but please be patient - I can’t help it.

People with Parkinson's do not have enough of a chemical called dopamine in their brain. The brain uses this to send messages to the muscles. Lack of it means people with Parkinson's become slow and stiff, and often their hands or bodies shake. It can be hard work to move at all.

The slowness, stiffness and shaking become worse over time. There are medicines which can help, but these also become less effective after some years, or work for only part of the day.

It is frustrating to take so long to do the simplest task, and embarrassing to hold other people up, but please be understanding and forgive the delay.

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I have Parkinson's

Sometimes I can't write my name!

- Even in these days of computers it is a great handicap not to be able to write things easily by hand.
- If possible please write things down for me.
- If that's not possible please be patient – give me time to write.

Often one of the first signs that someone has Parkinson's is that handwriting becomes very hard work. Finger movements may be very slow, it may be hard to hold a pen or pencil in a shaky hand, and the written letters get smaller and smaller until they are impossible to read.

It becomes even harder if someone with Parkinson's has to write something while upset or under pressure.

And if you are dictating something for me to take down over the phone, please speak very slowly and clearly.

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I have Parkinson's
Please give me a chance to get a word in!

- Give me space to say what I want to say.
- If possible choose a quiet place to talk in.
- Do your best to understand what I'm saying.
- Remember that I'm not daft, just finding it difficult to get the words out.

People with Parkinson's get very slow and stiff in their movements, and this affects their voice as well as walking and everything else.

Their voice may become very quiet and indistinct. If their face gets stiff too and their hands shaky, they won't be able to use smiles and nods or gestures to help explain what they mean. And because speaking is so tiring, they may not say very much.

And if someone with Parkinson's is upset, perhaps after an accident, it may be impossible to get any words out for a bit.

Please be patient.

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I have Parkinson's I switch "on" and "off" like a light!

- When "on" I can wash, dress, eat and walk by myself.
- When "off" I may need help with all these.
- So please don't assume that because I could go for a walk or use a knife and fork yesterday, or ten minutes ago, I can do it again now.

People who have had Parkinson's for some years often find that their pills work less well than before. They may slow down before they can take their next pill.

Sometimes instead of wearing off gradually the medicine switches off suddenly, just like a light switch going off. Then every movement becomes tiring and difficult, sometimes impossible or painful.

The switch can happen several times a day and at different times from day to day – it is difficult to predict when it will happen. Each day and hour has to be taken as it comes.

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I have Parkinson's

Sometimes I "freeze" on the spot!

- Sometimes I feel rooted to the ground.
- Or as if I have forgotten how to move for a moment.
- My hands or fingers can "freeze" too.
- You may be able to help. Try telling me to lift my foot or give me something small to step over.

People who have Parkinson’s find it hard to move – they can become very slow and stiff.

Sometimes they “freeze” suddenly. This can happen when they want to start moving, or are trying to get through a doorway or to turn round or change direction. Sometimes there is no obvious reason.

Arms or hands or fingers can “freeze” too as if they have forgotten how to set down a cup and let go of it. If that happens try taking the cup out of my hand.

I have Parkinson’s
I find it hard to smile or frown!

- It’s sad for me not to be able to show that I’m glad to see you.
- And hard for you if I seem unfeeling or not interested, or look as if I don’t understand.
- But please don’t take me at face value: there is a human being behind the mask.

People with Parkinson's get very slow and stiff in their movements, and some find that this particularly affects the muscles of the face. It becomes very hard work, sometimes impossible, to show any sort of feeling.

The muscles needed for speaking can be affected too, so that the voice may sound very monotonous and without expression. And because speaking is so tiring, we may not say much.

We can't help this. Remember we do have opinions and feelings, like anyone else.

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I have Parkinson's
I need to get my pills on time!

- I have my own individual mix of medicines.
- And my own individual timetable for taking them.
- I know if the dose or timing needs to change because of special circumstances.
- Please help me cope as best I can by seeing that I get my pills at my right time.

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Everyone with Parkinson's is different. One may have more difficulty moving than others, another more pain, one may get worse more quickly and so on. All find they have good days and bad days, good hours and bad hours.

One may get a lot of help from one medicine. Another may find a different one better. Some need stronger doses and a mix of several pills. Others may be better taking smaller doses more often. The timing of meals may also affect how well the pills work.

We have each worked out with our doctor what is best for us – please help us stick to this.

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I have Parkinson's
I find it hard to do two things at once!

- Sometimes my body seems to have forgotten how to move, and I have to think through how to do it.
- So I have to concentrate on one thing at a time - I may not be able to talk, or carry something, at the same time as I walk.
- Stress makes thinking and moving, or talking, even harder.

People who have Parkinson's do not have enough of a chemical called dopamine in their brain. Without it they can no longer move smoothly and naturally and become very slow and stiff. They have to think how to make each move. They may find that it is difficult to concentrate, and that they are slower at thinking a problem through.

Some therapy may be helpful. You can help too, for example, by providing a quiet place without distractions to talk in, and by not expecting someone with Parkinson's to do, or think about, more than one thing at a time.

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I have Parkinson’s
I can’t always be sociable!

- When my pills are working:
  - I can enjoy being out with friends or going to meetings.
  - I’m able to speak up for myself in a group.
- But when they don’t work:
  - I feel much less like talking to people or going out.
  - I feel much more anxious and easily stressed.
  - I find it harder to make decisions.

People with Parkinson’s do not have enough dopamine in their brain. As well as affecting movement, this can also affect feelings and attitudes.

There are medicines to help us move and these can also help us to remain more sociable and outgoing.

We can juggle our medicine to some extent, to fit what we want to do, but this must be planned ahead. So, for example, it really helps if a meeting starts on time and doesn’t overrun.

Even chatting can get stressful, so please understand when sometimes I go quiet and can’t join in so much.

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