

My Granddad has Parkinson's



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Written by Virginia Ironside with help
from families affected by Parkinson's.

Illustrated by Matthew Dodd.



I'd like to tell you a story.
A true story. It's about me and
something called Parkinson's.

Have you ever wondered what
Parkinson's is?

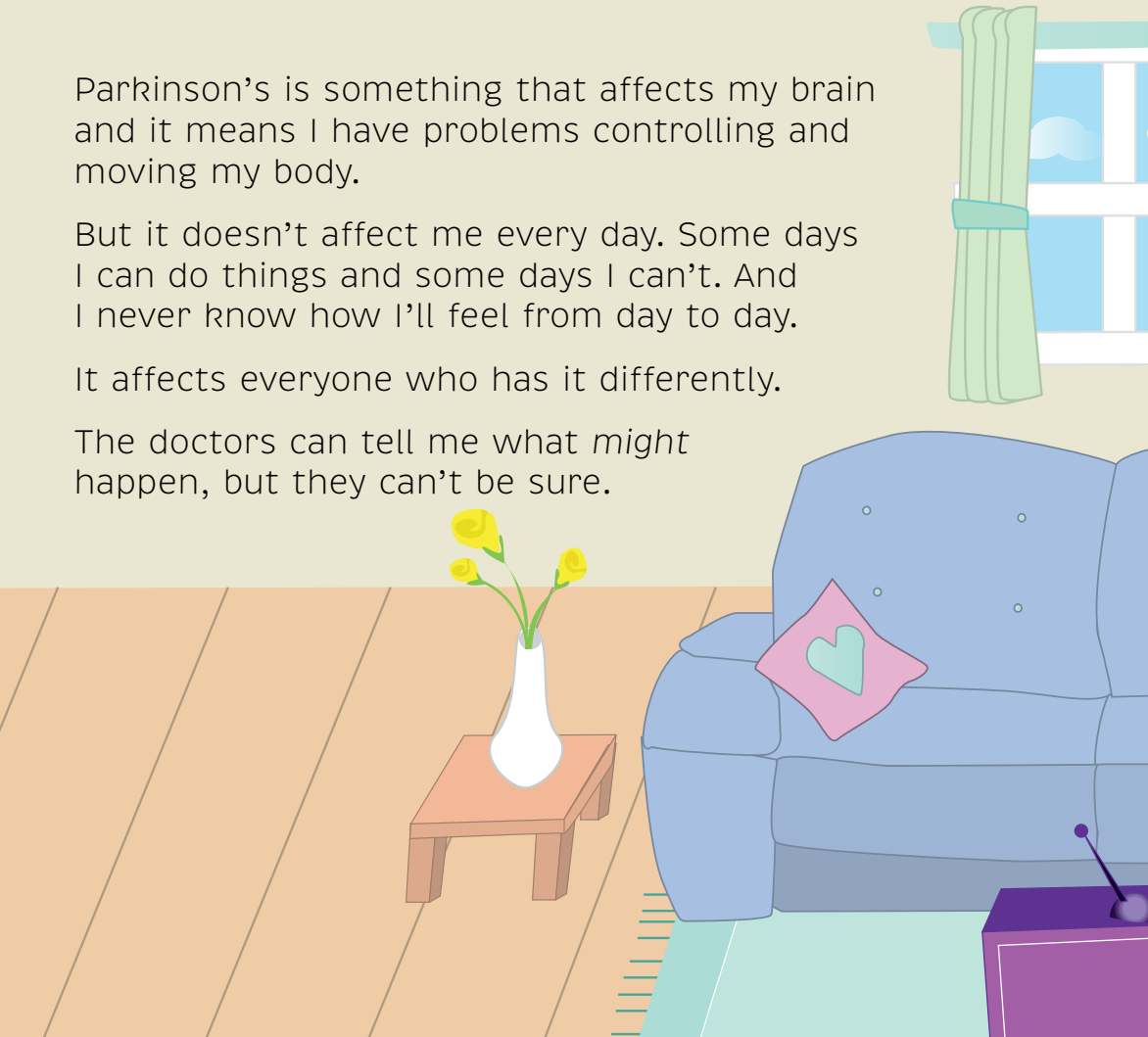
I'll try to explain it to you.

Parkinson's is something that affects my brain and it means I have problems controlling and moving my body.

But it doesn't affect me every day. Some days I can do things and some days I can't. And I never know how I'll feel from day to day.

It affects everyone who has it differently.

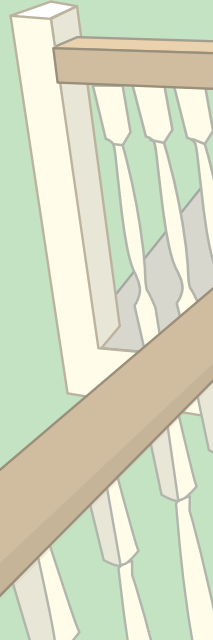
The doctors can tell me what *might* happen, but they can't be sure.





Now you're probably wondering where I got Parkinson's from. Did I catch it, like a cold? No, I didn't. And *you* can't catch it either.

The problem is no one knows exactly where it comes from.







Most people live with Parkinson's for a very long time. Even though it can get worse, it gets worse very slowly.

And in case you're worried, it's very unlikely you'll get it when you're older.

The doctors can give me pills to help make life easier, but they can't make it go away yet.



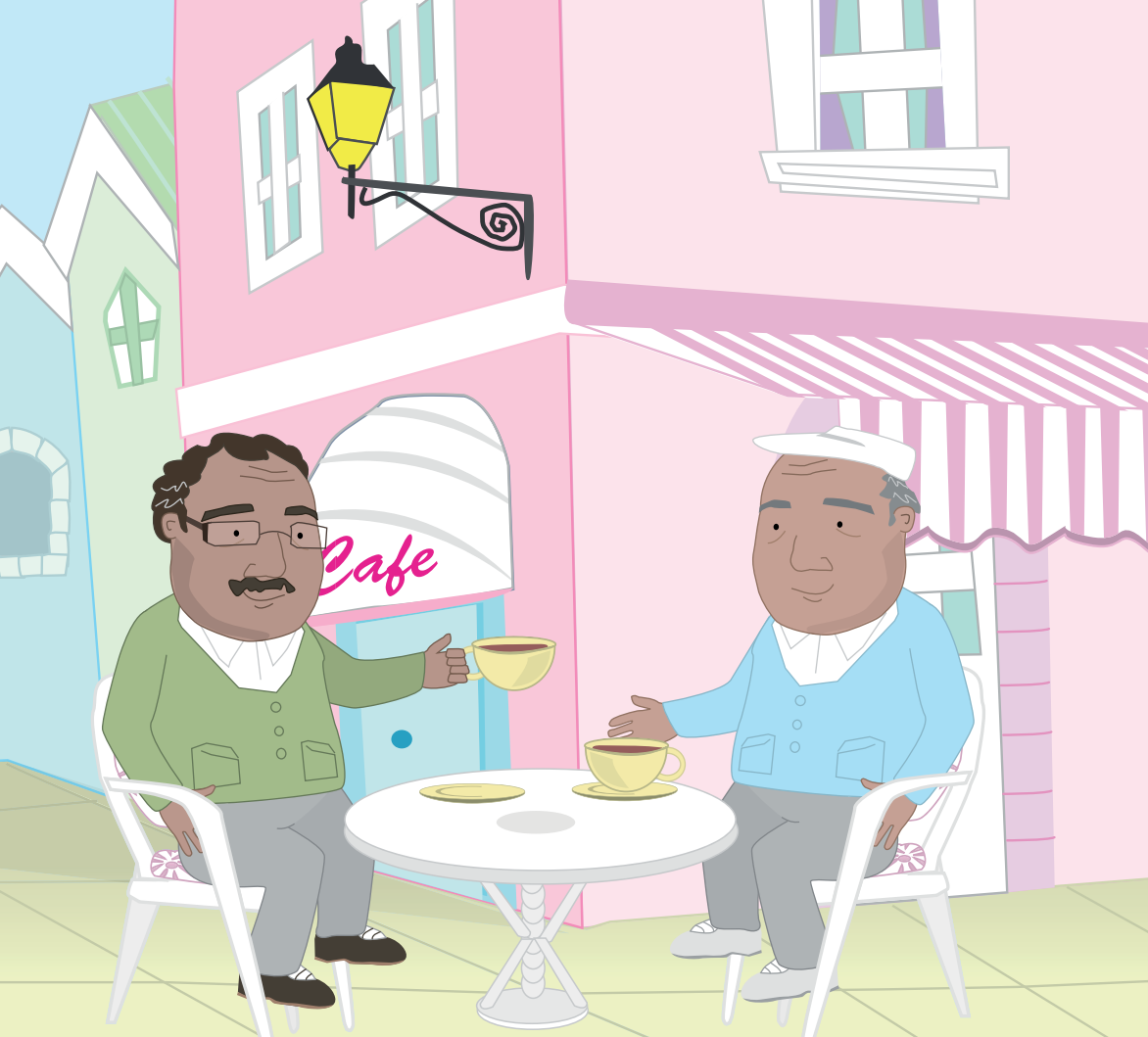
Scientists are working hard to find out how to make it go away or stop people getting it.

But until they find a way to make it go away, Parkinson's means I may not be able to do all the things I want to, when I want to.

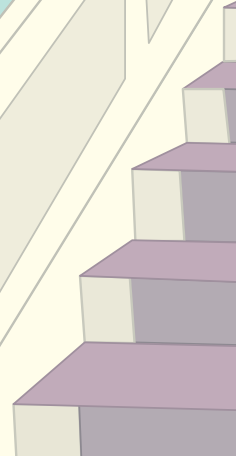
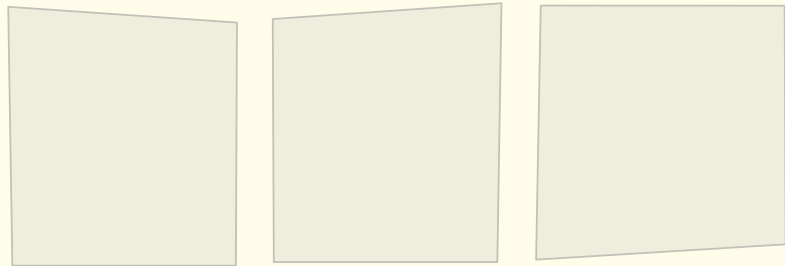
Sometimes my hand may shake a little. It doesn't stop me shopping or seeing my friends.



GREEN LANE



But I may not be able to
tie my shoelaces that day.
It's really annoying!





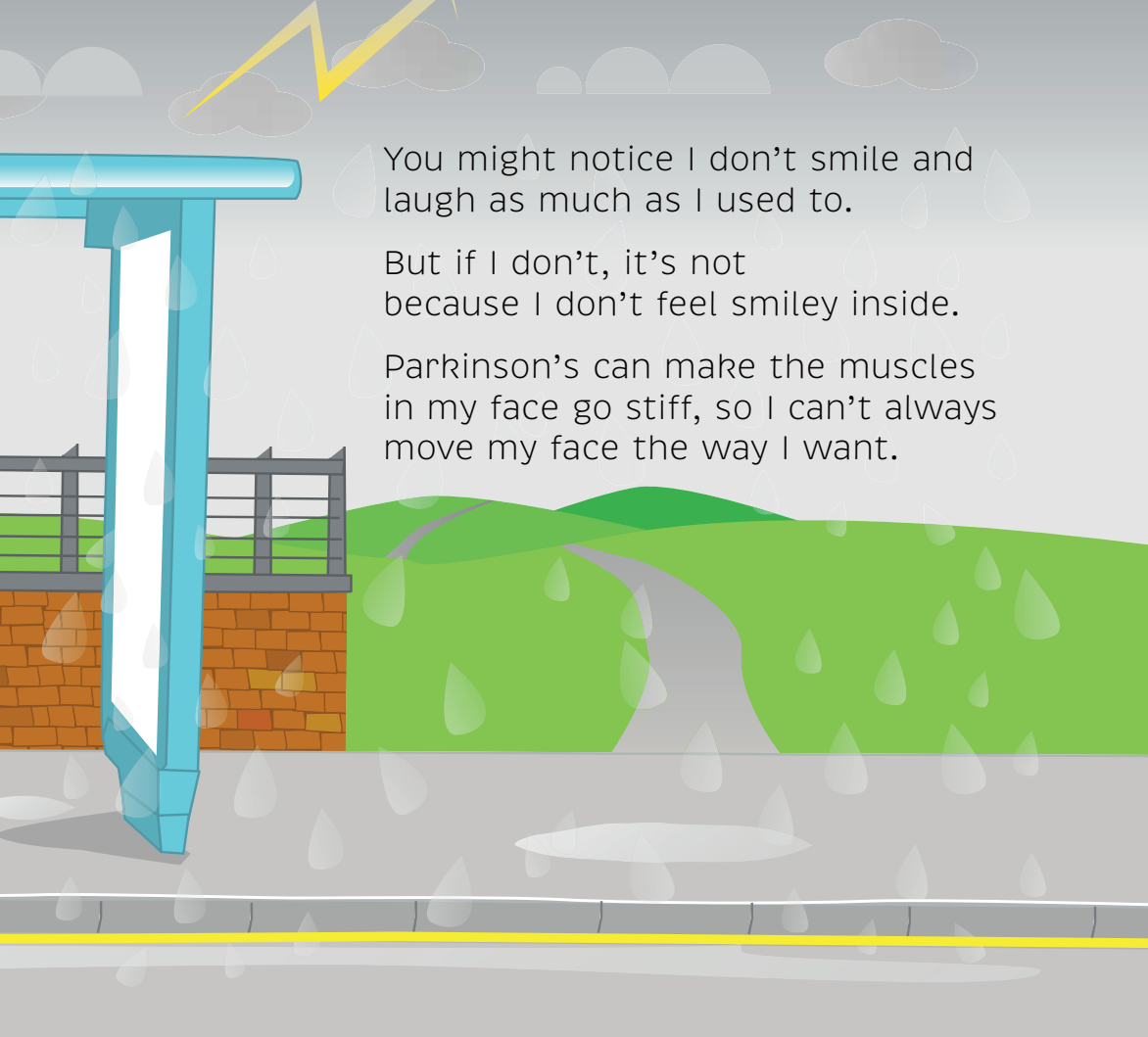


Bus Stop

Local Park
Number 4 Bus

traveltime





You might notice I don't smile and laugh as much as I used to.

But if I don't, it's not because I don't feel smiley inside.

Parkinson's can make the muscles in my face go stiff, so I can't always move my face the way I want.

Can you imagine what it would feel like
if you wanted to smile but couldn't?

Can you keep a straight face even when I tickle you?

You're giggling because the muscles in your face are
working very well, so you can laugh when you want.
But mine don't work quite as well as yours.





And it's not just the muscles in my face that are stiff. Parkinson's makes all the muscles in my body stiff.

This means that I sometimes can't move around as well as I used to.

Some days I can't rush about or do the cooking or the washing up like I used to – I worry I'll drop a plate!



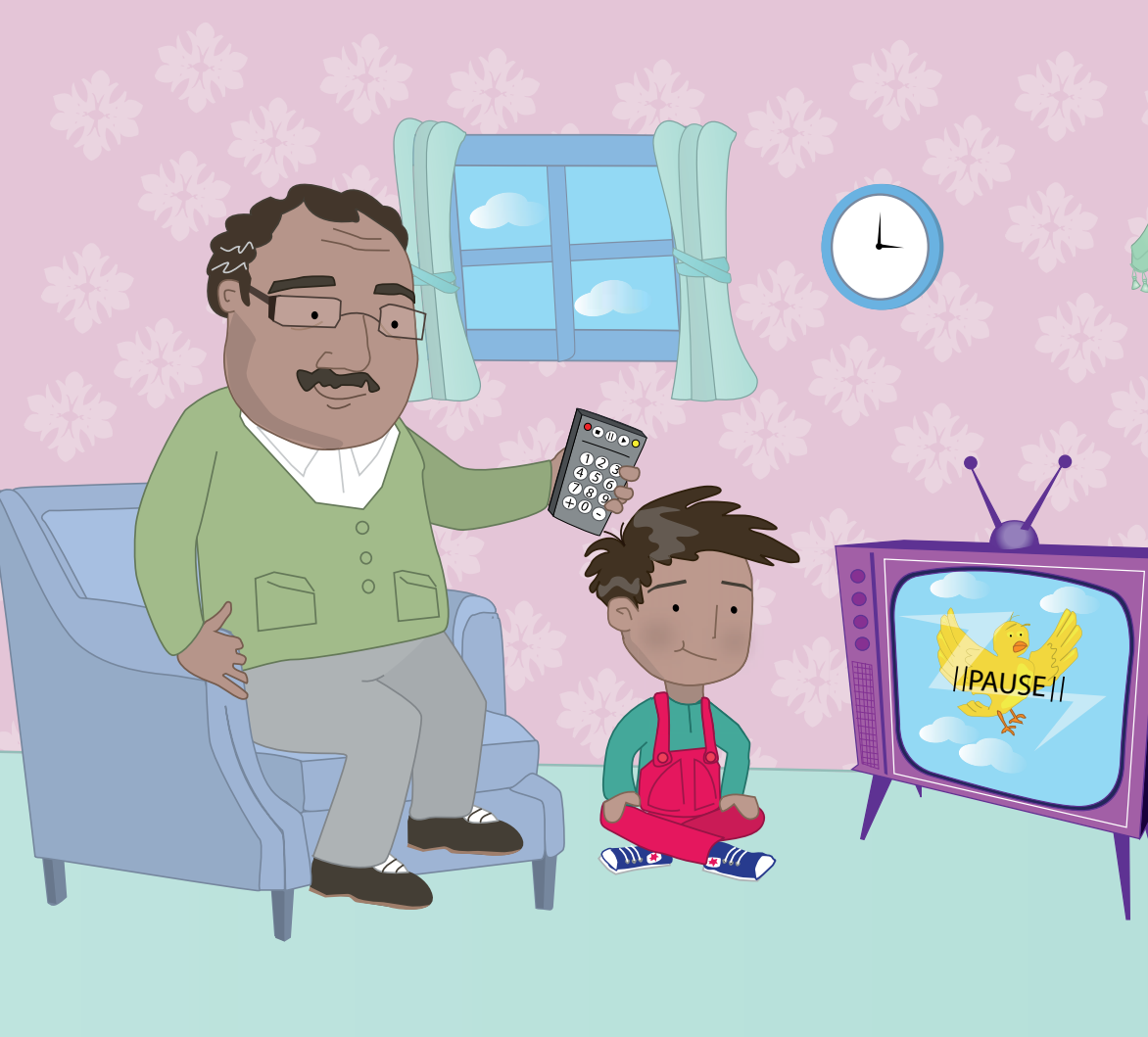




Of course it makes me a bit upset and cross to find I can't do things I want to do.

Especially when it means I can't play with you as much as I used to.

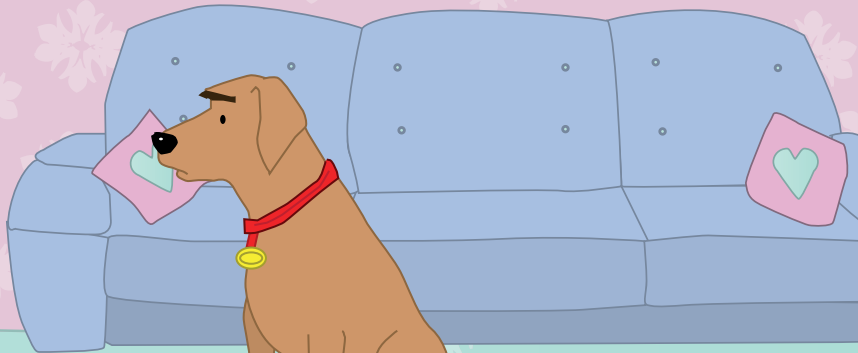




You might have noticed that sometimes I just stop walking for no reason. I want to go on walking, but my muscles don't want to move – they freeze up.

It's rather like when you press 'pause' on the DVD and it stops until you press 'start' again.

But you can't press 'start' on me. If you leave me for a bit, I'll soon get going again.



Sometimes I might
even fall over.



Just like you did
when you were
learning to walk.

And it's annoying when I can't eat my tea properly. But having Parkinson's means it takes me longer to lift my spoon and swallow than it used to.





In a few years it may mean I can't speak as well as I do now. My voice may get quieter – so it sounds as if I'm whispering.

Can you hear what I'm saying if I'm whispering?



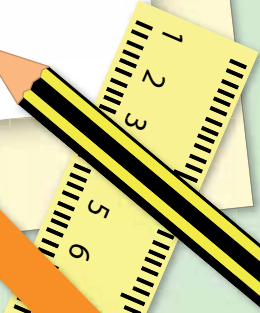
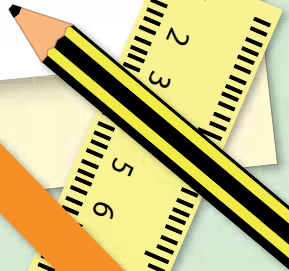
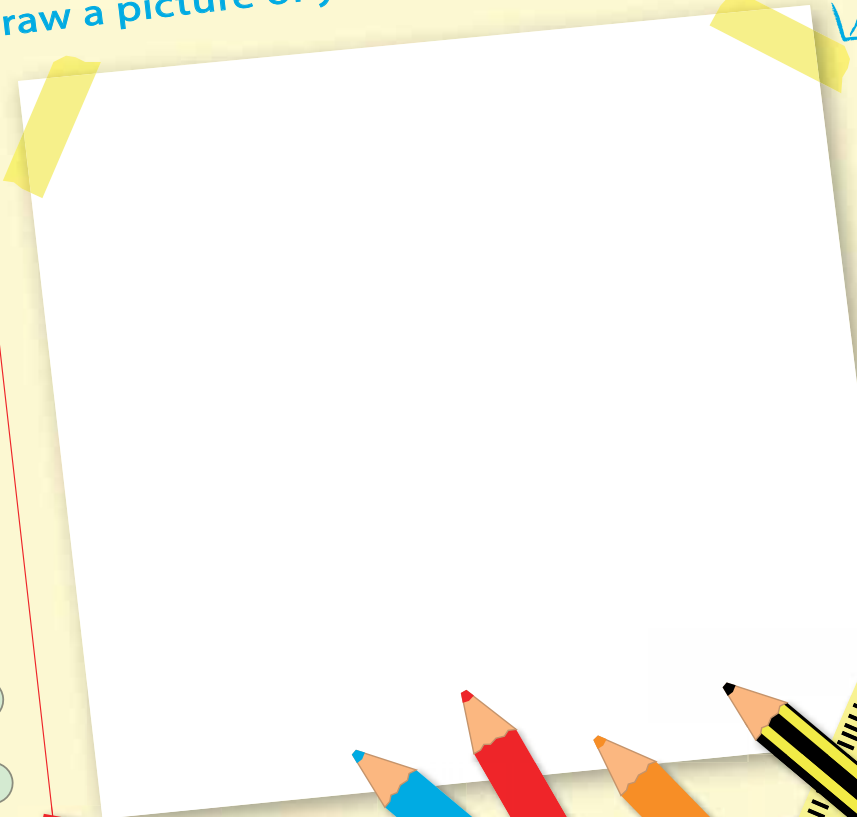


And my writing and drawing might
get really small and messy, like yours
when you're in a hurry.

But I'll still be able to give you cuddles!



Draw a picture of you and your Grandad here



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If you have any comments about this book, we'd love to hear from you. Visit parkinsons.org.uk/informationfeedback, email publications@parkinsons.org.uk or write to us at the address on the back page.

Thank you to everyone who contributed to or reviewed this book:

Michelle Hampson, Educational Psychologist

Katie Byard, Clinical Psychologist

Julie Keogh, Information and Support Manager, Parkinson's UK

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

Our information

All of our most up-to-date information is available at

parkinsons.org.uk/information-support

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**.
Thank you.

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK

215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**

(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk
parkinsons.org.uk

Grandad wants to tell his grandson a story. A true one. He has something called Parkinson's and he wants to make sure his grandson knows what that means – and show him that he's still the same old Grandad!

Using everyday settings and places, this book aims to help explain to children aged three to seven what Parkinson's is and how it can affect people with the condition.



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