

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

FINDING A CURE,  
AND IMPROVING  
LIFE FOR EVERYONE  
AFFECTED BY  
PARKINSON'S.

Parkinson's UK  
Our plans  
2010–2014



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“I hope you will support our desire for the charity to become better known so that we can reach out and help more people than ever before.”

**W**elcome to the new strategy for Parkinson's UK. For more than forty years

our charity has been working to improve life for everyone affected by Parkinson's. In that time, we've invested more than £45million in research, secured 280 specialist Parkinson's nurses, and provided information, friendship and support to hundreds of thousands of people.

But we're still not reaching everyone that needs us. And we still don't have a cure. So there is much more for us to do.

This is why we have been listening carefully to the hopes of the people we work with and those who need our support. This has helped us to identify a clear vision for the future: **to find a cure and improve life for everyone affected by Parkinson's.**

Keep reading to find out more about our plans to achieve our ambition. We still have a lot to do, and we can't do it alone. We need to harness the knowledge, skills and enthusiasm of everyone involved in the work of Parkinson's UK, whoever they are. Only by working together can we make our vision a reality.

Whether or not you live with Parkinson's every day, as my family does, I hope that you will support our desire for the charity to become better known so that we can reach out and help more people than ever before.

**Melinda Letts** Chair



“Our vision for the future is to find a cure, and improve life for everyone affected by Parkinson’s. Our strategy is focused on delivering that ultimate ambition.”

Over the last few years, we’ve achieved lots of great things. We’ve expanded the range of support available to people affected by Parkinson’s, making sure everyone has access to a local Information and Support Worker. We’ve improved professionals’ knowledge and understanding of Parkinson’s and used our influence to improve health and social care services. And we have invested more than ever before in research, establishing a leading role internationally, as we urgently pursue a cure.

Our new strategy is based around three key areas – **reaching out**, **driving change** and **growing strong**.

We are determined to **reach out** to everyone living with Parkinson’s, to make sure they all know about us and the support we offer. We’ll build on our current services so that people can engage with us quickly and easily when they want to.

While health and social services have improved for some people, that isn’t the case for everyone. We’ll use our influence to **drive change** to ensure national standards are implemented across the UK, so that everyone has access to a specialist Parkinson’s nurse. We are also going to push our search for a cure to a new level, using our own resources to fund groundbreaking research, as well as persuading others to do the same.

To achieve our ambitions we must **grow strong**. We must increase our income by raising more than £27million by the end of 2014. That’s an 11% increase per year. It means inspiring lots more people to support us.

Over the last year we have reviewed our brand, including defining who we are, as well as updating how we write and how we look. The entire brand has been created in consultation with a wide variety of people. The elements that make up the brand – the words, the colours, the images and the logo – have been carefully selected to show who we are, have the widest possible appeal and attract new supporters. We are confident that our new brand will help us make a bigger impact.

By increasing our profile we can help more people than ever before and find a cure quicker. But we can only do it with your enthusiasm and commitment. Thank you for supporting us.

**Steve Ford** Chief Executive



# HIGHLIGHTS FROM 2007-2009

Our 2007-2009 strategy had two priorities.

The first was to implement our *Support for All* programme and expand our local teams. This would enable the whole charity – local groups and staff – to have a greater impact.

# 9,882

In 2006, less than a third of people living with Parkinson's had access to a local Information & Support Worker. Now, we have a national network providing support to 9882 people per year

## AWARENESS

Our *Get it on Time* campaign has increased awareness of the need for timely medication management in hospitals and care homes.

# INVOLVE

People living with Parkinson's are now much more involved in our campaigning and policy work.

# 289

We've increased the number of specialist Parkinson's nurses in the UK from 227 in 2006 to 289 by the end of 2009.

# 1,000

In 2006 we delivered around 300 training sessions to health and social care professionals. We now deliver over 1,000 sessions a year.

The second priority was to implement our *Research Strategy*. This involved spending more money on research and using our leadership and influence to support Parkinson's research internationally.

# £4.7M

We have increased the total we spend on research from £4.2million to £4.7million each year.

## INVEST

We have invested in the next generation of Parkinson's researchers through the development of the PhD Studentship and Career Development Awards.

## INNOVATION

We have introduced innovation awards to encourage more cutting-edge research.

## LEADERS

We have established ourselves as leaders in research with a focus on finding a cure.

# £5M

We have secured £5million funding from the Monument Trust and identified a high-quality research team to embark on a long term, cure-focused project.

An elderly man with white hair, wearing a tan jacket over a blue sweater and a plaid shirt, stands on a balcony overlooking the ocean. He is holding a white sign with blue text that reads "HELP US REACH EVERYONE WHO NEEDS US". The background shows a blue sky with scattered clouds and a white railing in the foreground.

**HELP US  
REACH  
EVERYONE  
WHO  
NEEDS US**

# OUR VISION, MISSION AND VALUES

## OUR VISION (our ultimate ambition)

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**TO FIND A CURE, AND IMPROVE LIFE FOR EVERYONE AFFECTED BY PARKINSON'S.**

## OUR MISSION (what we do)

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### Research

We fund groundbreaking research to advance understanding of Parkinson's and improve treatments. We'll overcome the symptoms and find a cure.

### Information

We provide expert information and training on every aspect of Parkinson's.

### Friendship and support

We offer friendship and support to everyone living with Parkinson's, and their families and carers.

### Campaigning

We raise awareness, change perceptions and demand better services.

### Fundraising

Our work is totally dependent on donations. We inspire people to support us.

More people need to know what we stand for. Although we've always been here for people with Parkinson's, we've sometimes struggled to explain that in a clear, simple way. Our brand project has enabled us to rediscover who we are and clarify what we do. This is summarised in our vision, mission and values.

## CORE VALUES (the way we work together)

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### We listen

Everything we do is based on the experiences of people affected by Parkinson's.

### We focus

We deliver results and make the most of our resources.

### We inspire

Our energy and determination inspire those around us.

### We innovate

We are forward-thinking, always seeking to improve.

### We're passionate

We go the extra mile.

### We're united

We work together as one organisation united behind one shared vision.

## BRAND VALUES (the way that we communicate)

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### Short

We get to the point. We say what we think.

### Simple

We use friendly conversational English.

### Bold

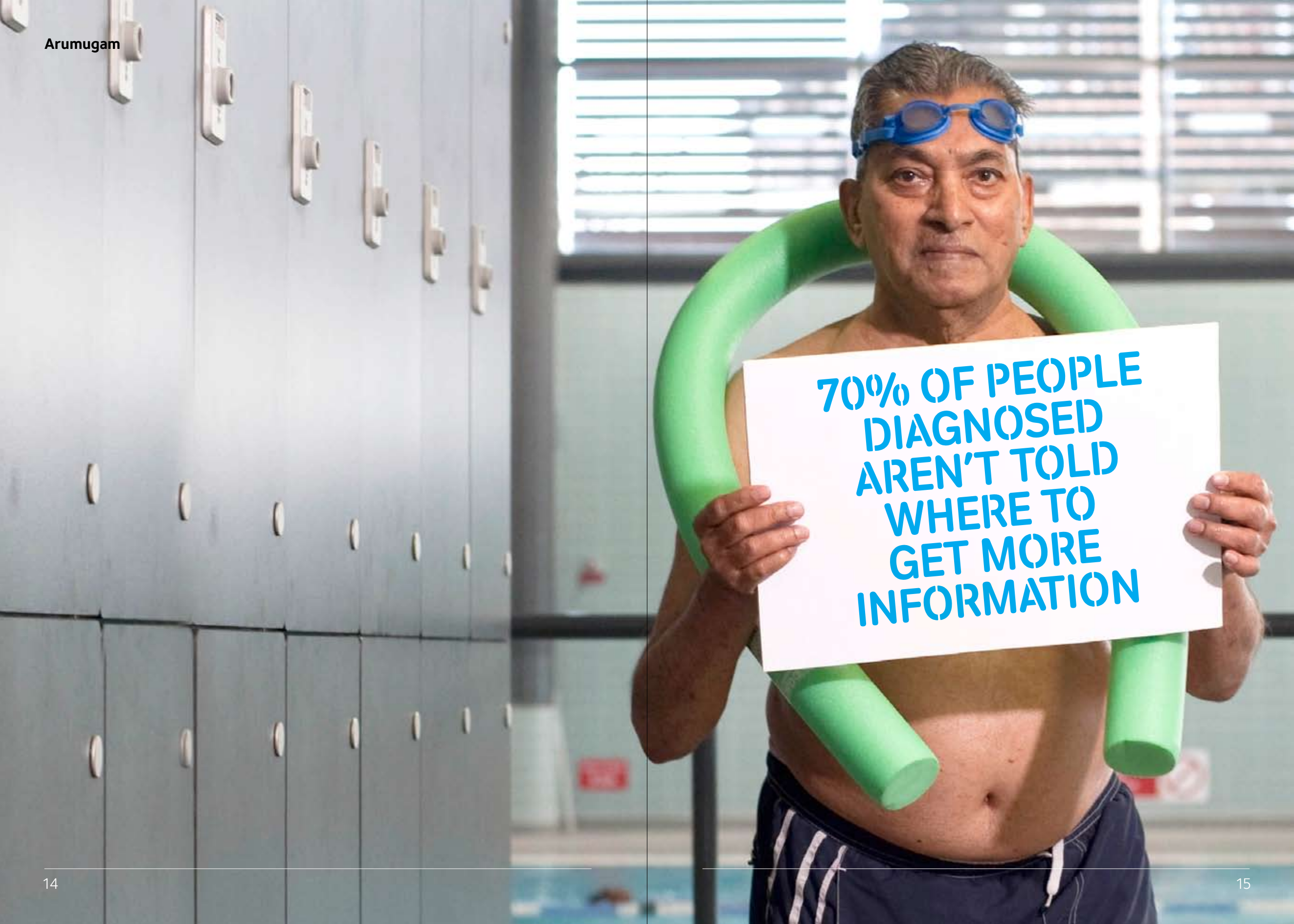
We stand out from the crowd.

### Bright

We're lively, positive, and upbeat.

### Human

Our personality shines through.



**70% OF PEOPLE  
DIAGNOSED  
AREN'T TOLD  
WHERE TO  
GET MORE  
INFORMATION**

# GOAL 1

**F**acing Parkinson's can be a lonely experience. Too many people tell us that when they were diagnosed nobody gave them the information and support they needed. They didn't even know our charity existed. We have to change that. We need to make sure that health and social care professionals are always aware of what we offer, so they refer people to us as a matter of course. We want everyone to know about the information, support and friendship we can provide.

No one will have to face Parkinson's alone

## By 2015

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We'll have reached out to everyone living with Parkinson's.

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All Parkinson's healthcare professionals will know about Parkinson's UK and understand what we do.

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We'll have doubled the number – and increased the diversity – of people using our information and support services.

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People affected by Parkinson's will be able to get in touch with each other more easily, and in a variety of ways.

## We will

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Conduct research into how many people have Parkinson's and their demographics.

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Promote our information and support services for people with Parkinson's to healthcare professionals through a range of marketing channels.

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Strengthen the networks that give people affected by Parkinson's, and volunteers, the opportunity to share experiences and support each other.

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Tailor our information and support services to meet the needs of everyone affected by Parkinson's, identifying and targeting those we currently don't reach.

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Maximise opportunities to raise the profile of the charity to make sure that everyone affected by Parkinson's is aware of our services.

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Improve our use of social media networks and digital communications to engage and support people living with Parkinson's, their carers, families and friends.

# JOHN

"I was 19 when I was diagnosed. It took a year for it to sink in. I was worried about what would happen as I grew older. Being young made me feel really isolated.

Parkinson's UK helped me to understand the condition, giving me and my family the information we needed to make sense of it all.

It sounds weird, but being diagnosed has given me a new calling in life. I'm in a position to help others and raise awareness about Parkinson's. This has given me something positive to focus on, which has helped me to cope."



# GOAL 2

**T**he experiences of people living with Parkinson's must be at the heart of everything we do. Only by carefully listening to real-life experiences can we provide truly responsive services. Our close contact and involvement with people living with Parkinson's is one of our strengths. We will channel the views and voices of everyone affected by Parkinson's to improve policy, advance research and secure better services.

We will listen and respond to the needs of everyone affected by Parkinson's.

## By 2015

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Everything we do will be informed by the views and experiences of people living with Parkinson's, their families and carers.

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Appropriate information and support will be available for everyone affected by Parkinson's – at every stage in their journey.

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We'll establish high quality standards across everything we do – focusing on what people with Parkinson's need and value the most.

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We'll ensure our research programme is shaped by and accountable to people with Parkinson's.

## We will

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Involve people with Parkinson's in developing and monitoring everything we do.

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Make sure our information and support services compliment each other, and are made available to everyone we come into contact with.

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Use the experiences of people living with Parkinson's to put together information and support packages for people at all stages of the condition.

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Continuously improve the quality of the services we offer and demonstrate this through monitoring and external accreditation.

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Develop and support a global network to allow people affected by Parkinson's to be involved in a variety of research activities.



# LINDA

"I first thought something was wrong when I started to have problems walking. It felt like someone was holding my legs when I tried to move.

When my doctor told me he thought I had Parkinson's my first thought was – why me? I'd always been healthy and active and so it took a while to sink in that it was here to stay. When it did sink in it hit me hard. I didn't think I'd be able to live a normal life again.

Attending Parkinson's UK's local exercise classes made me see that other people exactly the same as me were coping well. It made me realise that I wasn't alone, which was very comforting."

# GOAL 3

**E**veryone affected by Parkinson's should be able to access health and social care that meets national quality standards. Yet the services people get today depend on where they live. This is unfair and can't go on. We need to use all possible levers to improve care and make sure everyone can benefit from good services, including support from a specialist Parkinson's nurse. Through our powerful new brand, information, training and campaigning, we'll advance understanding of Parkinson's and continue to improve services.

We will improve life for everyone affected by Parkinson's.

## By 2015

We'll make sure everyone has access to a specialist Parkinson's nurse wherever they live.

Our training and resources will enable health and social care professionals to deliver better care.

We'll raise public awareness and understanding of Parkinson's and Parkinson's UK.

We'll improve the quality of care people receive, by enabling people affected by Parkinson's to make better informed choices about their health and social care.

## We will

Campaign to ensure national standards for Parkinson's care are implemented across the UK.

Influence local service planners and commissioners to provide comprehensive services for people with Parkinson's everywhere, including specialist Parkinson's nurses.

Promote our training and information resources to all health and social care professionals, and continually develop them using feedback to ensure they are relevant.

Work to improve understanding of Parkinson's and change misconceptions.

Encourage information sharing among local services to drive up standards and improve best practice.

# HYWEL

"I first thought something was wrong when my shoulder started to freeze. When a neurologist told me I had Parkinson's I felt numb – I was devastated.

I used to think there was nothing easier than walking, putting one foot in front of another. Not anymore. It is so frustrating.

The most important thing to happen to me after being diagnosed was meeting the Parkinson's nurse. She was fabulous. She told me from the start that it wasn't the end for me. I just had to choose a new life journey, which I feel that I've done.

My local Parkinson's UK group have been incredibly supportive. They've helped me realise that you've got to cope, to adapt and to live with it. I've continued working full time for 11 years since I found out. You've got to be positive. Life goes on."



# GOAL 4

Innovative research is fundamental to achieving our vision – finding a cure. By the end of 2009 the charity had spent over £45million on research. However, it is vital that we increase our investment in research to bring us closer to cure.

We can't find a cure completely on our own, and so we'll work closely with other charities and Government-funded research bodies to ensure that Parkinson's remains at the top of the research agenda. Sharing research findings is also critical to success, and so we'll improve opportunities for collaboration in the UK and across the world.

Our research will have resulted in better treatments and progress towards a cure.

## By 2015

We'll have invested more than £25million in innovative, high-quality research, and increased the amount of money spent on Parkinson's research within the UK.

We'll drive forward the UK Parkinson's research agenda, making sure it delivers maximum impact and investment in treating and curing Parkinson's.

We'll increase the proportion of money we spend on cure related research.

We'll effectively communicate the outcomes and benefits of our research to raise our research profile, build momentum and inspire support.

## We will

Work with other funding bodies to ensure Parkinson's research gets more funding.

Monitor Parkinson's research taking place around the world in order to identify pivotal developments.

Communicate our research priorities to researchers.

Promote innovation grants to accelerate the progress of research.

Publish annual reports on the charity's research grants to monitor the quality of research.

Communicate the impact our research has on the lives of people living with Parkinson's.



# KAREN

“My Dad first noticed something was wrong on holiday when I couldn’t swing my arm properly. The doctors initially thought I had RSI or MS. It took them over four years to diagnose me with Parkinson’s. My first thought was that I’m not old enough – that it’s a disease for old people. I was very depressed when I realised it would be with me for the rest of my life.

The nurse put me in contact with my local Parkinson’s UK group. I was quite reluctant at first as I felt too young, but then I met people nearer to my age. Having people to talk to who are going through the same thing is so important, as most people just don’t understand. Parkinson’s UK has supported me by giving me the opportunity to meet others.

One day I hope research will find a cure, or at least a better way to control the symptoms.”

# GOAL 5

**T**he charity has achieved so much since its foundation in 1969 – providing services to people with Parkinson’s in communities throughout the UK. The last five years has seen a huge investment in growing the services we offer, but only by spending more money than we’ve raised, and recently against volatile economic conditions.

Our local groups and fundraising teams – alongside thousands of supporters and volunteers – have played a key role in providing the firm financial foundations that underpin our work. But we can’t stop here if we are to reach everyone affected by Parkinson’s in the UK by 2015. Over the next five years, we must all pull together to raise more money to achieve our ambitious plans.

We will raise more than £110million to meet the costs of delivering our ambitious plans.

## By 2015

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We’ll have given more people than ever before the opportunity to get involved and support us, locally and nationally, through an innovative range of fundraising activities.

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We’ll have significantly increased the number of individuals and organisations who donate to the charity on a regular basis.

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We’ll have significantly increased our income from trust, major donor and corporate supporters from £1million to over £3.5million annually.

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We’ll have significantly increased the number of people who pledge a gift to us in their Will.

## We will

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Inspire every individual, group and organisation that comes into contact with the charity to support us.

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Grow our regional fundraising team to help our local groups boost their fundraising.

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Harness our networks of people living with Parkinson’s, their carers, family and friends, health and social care professionals, to find new and committed supporters.

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Tell all new and existing supporters about the importance of legacies and how they can leave us a gift in their Will.

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Identify and develop more effective ways for people to get involved and support us.

# ALUN

"I thought it was the end when I was diagnosed. I sat down with my wife and we just cried. Now, looking back, I can see that the whole experience has changed me for the better. I've done so many new things and have a different outlook on life now.

The main problem is the frustration, because you can't do things, pain because it physically hurts, or anger at the fact you've developed it. Parkinson's UK helped us deal with all these things. They gave us someone to turn to and put us in touch with people going through the same thing."



# GOAL 6

One of our main strengths is our people – our enthusiastic network of local groups and committed staff. We don't always make the most of this strength. Our brand research identified that sometimes we pull in different directions, despite all working for the same cause.

Our new brand and strategy provide greater clarity about who we are and what we do. They provide a fantastic opportunity to drive the charity forward and make us stronger. Our vision, values and goals will keep us on track and make sure we all share a common sense of purpose. We also need to make sure we have the right resources, technology and staff to be effective and deliver on our promises. Only by working together will we achieve our vision.

We will be a united, focused and effective organisation.

## By 2015

Everyone involved in Parkinson's UK will share a common vision, understanding how their work contributes to achieving our ultimate ambition.

We'll have increased the number of volunteers supporting us.

We'll make better use of information to understand the needs of people affected by Parkinson's and our supporters.

We'll be able to demonstrate the difference we make and prove that we are making the most of our resources.

## We will

Embed a strong brand across the charity with a shared vision and values.

Improve our internal communications to keep everyone up-to-date.

Create an organisation-wide database to provide a seamless service to people affected by Parkinson's and our supporters.

Inspire more volunteers to support us.

Empower our staff to work together with effective internal systems, recruitment and performance management that reinforce our values, supported by appropriate learning and development.

Review the way we operate on an annual basis to make sure we are delivering our vision as quickly as we can.

Monitor and publish the impact of our work and the difference it makes to people affected by Parkinson's.



# DENNIS

“Parkinson’s can happen to anyone. I’d been working as a consultant, flying here, flying there. That’s all behind me now. I was diagnosed 3 years ago and felt scared and alone when I found out. Everything seemed uncertain and I didn’t know what the future held.

No one seemed to understand what I was going through – except for Parkinson’s UK. They gave me someone to talk to and are working hard to find a cure, which would remove the uncertainty from my life.

Everyone, including my family and friends, began to rally around me, which was amazing. After 6 months I realised that I just had to get on with my life. Parkinson’s UK helped me do this.”

**TOGETHER  
WE CAN  
BEAT IT**

# Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

## Parkinson's UK

215 Vauxhall Bridge Road  
London SW1V 1EJ

Free\* confidential helpline **0808 800 0303**

Monday to Friday 9am – 8pm

Saturday 10am – 2pm. Interpreting available.

Textphone **0800 111 4204**

\*calls are free from UK landlines and most mobile networks.

Visit us online at [parkinsons.org.uk](http://parkinsons.org.uk)

Drop us a line at [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

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