

# EMPLOYMENT AND PARKINSON'S

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



## If you have Parkinson's, or you care for someone who does, you may have concerns about your working life.

Whatever your circumstances, this guide is full of information to help you make informed decisions about your working life. It includes details about what your legal rights are in the workplace, how you can adapt the way you work and what your options are for the future.

If you have any concerns about how Parkinson's may affect your working life, we are here to help. Ring our helpline on **0808 800 0303** to speak to our benefits and employment adviser.

## Disclaimer

We've made every effort to make sure the information in this booklet is correct at the time of printing. But Parkinson's UK cannot take responsibility for the correctness, sufficiency or completeness of this information or any recommendation.

This guide does not constitute, and is not intended to be a substitute for, legal advice.

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“ Work is very important to me. It provides a sense of purpose and there’s a long way to go in my specialist field – I can’t leave yet.

The worst thing is hearing colleagues say, “So-and-so has let us down, they can’t come in today.” One day, that person will be me. I hope they know it’s not me letting them down, it’s my body!

I don’t expect to stop working any time soon, but I know it’s going to happen one day. So it’s very important that I know what options I have.

I told my employers that I have Parkinson’s, but since then I have tried to keep a low profile. I work in a very stressful job and I don’t want people to think I can’t do it because of my condition, because I still can.

I’ve spoken to my union about employment rights, pensions, sickness, when to involve occupational health, when to ask for support from my union – everything. I’ve also spoken to a careers adviser about possible alternative careers I can have when I can’t do what I do now. I need to find something, as I need goals.

My advice to people with Parkinson’s who are working is equip yourself with as much knowledge and information as you can, now. Get advice from your union, Citizens Advice and the Parkinson’s UK helpline. Don’t wait till crisis point, take control. ”

**Garth, diagnosed 2008**

# HOW CAN PARKINSON'S AFFECT MY WORKING LIFE?

Work is not only a way of making a living, it can also be important for confidence, self-esteem and personal satisfaction.

If your treatment is carefully managed and you have plenty of support, it is possible to continue working for many years, depending on the type of job you have and how Parkinson's affects you.

Speak to your GP, specialist or Parkinson's nurse about treatments to help you manage your symptoms and stay in work.

Sometimes, changes need to be made to make work easier, such as reducing your hours, changing career or taking early retirement.

If you are in paid work and care for someone with the condition, you may find that, as time goes on, combining your responsibilities can be challenging. You may also need to make changes to maintain your general health and wellbeing.

The most important thing to do is to stay as informed as you can about what your rights are in the work place and use all the support networks available to you.

## **I have Parkinson's. How am I protected against discrimination in the workplace?**

Because Parkinson's is a long-term condition you are likely to meet the statutory (legal) definition of disabled under the Equality Act 2010, or the Disability Discrimination Act 2006 in Northern Ireland.

This means that it is unlawful for an employer to discriminate against you because of your disability or because of something that happens as a consequence of your disability.

Employers also have a duty to make changes to the way you work to help you continue doing your job. These are known as reasonable adjustments (see page 14).

These laws protect anyone who has a physical or mental impairment that has a long-term, substantial adverse effect on their normal day-to-day activities.

## Will I still be protected during periods when I'm feeling fine?

Yes. The law protects people who have fluctuating conditions like Parkinson's, which are likely to change and develop over time. This means that you are still protected even when your symptoms are not having a negative effect on your ability to do 'normal' day-to-day activities.

In this case 'normal' activities are those that are normal for a large number of people, and carried out by people on a daily or regular basis.

These activities may include:

- walking
- reading and writing
- carrying or moving things
- concentrating and learning



# LOOKING FOR A JOB WHEN YOU HAVE PARKINSON'S

If you are looking for a job you may be wondering about how much you should tell a possible employer about your condition.

This section looks at what you have to tell your employers about your condition and what is positive discrimination.

## Do I have to tell potential employers that I have Parkinson's?

### In Northern Ireland

Here, employers are still allowed to ask questions about health and disability before making a job offer and may ask you to complete a pre-employment health questionnaire.

You should answer the questions on the form honestly. But remember that the Equality Commission for Northern Ireland says that a response to a medical questionnaire, the results of a medical examination or the opinion of a Medical Adviser should only be one of a number of

factors that an employer should consider in reaching their final decision about who to hire.

In particular, your potential employer should also consider what reasonable adjustments, if any, may be required. They should then make their selection decision following an assessment of how you would perform in the job if these reasonable adjustments were made.

### In Great Britain

It is against the law for a potential employer to ask you about your health or any disability before offering you a job, except in very limited circumstances.

You should only be asked health-related questions when they're necessary for certain purposes, including the following.

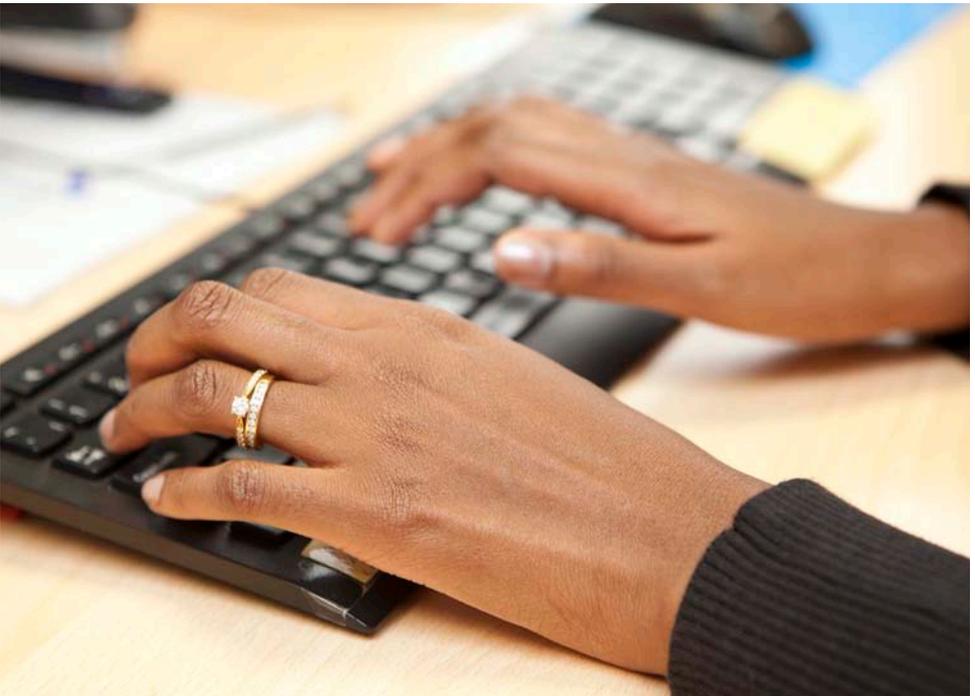
- If a potential employer is trying to find out whether you need any changes or reasonable adjustments to be made to the recruitment process (for example, the time or

place of the interview because of a disability or health condition).

- If you are applying as a disabled person under the government's 'Two Ticks' symbol (see the section on positive discrimination on page 11) or any similar schemes to improve employment rates for people with a disability. Note that the Two Ticks scheme is not applicable in Northern Ireland.
- For monitoring purposes. Potential employers can ask you to complete a form giving your race, gender, sexuality, religion, age and if you have a disability. Filling in these forms is usually

optional and should not be part of your application.

- If a potential employer is trying to find out if you have a disability or health condition that would affect your ability to carry out an essential part of the job. For example, if you were applying for a job as a builder your employer could reasonably ask you if you have any condition that would affect your ability to climb scaffolding and work at heights.
- If they require an employee to have a particular disability or condition as part of the role they are recruiting for.



## Deciding whether to tell an employer about Parkinson's

It is up to you whether you tell anyone about your condition.

You only need to tell a potential employer about a disability if any of the following applies to you.

- If you think your Parkinson's may cause a health and safety risk either to you or to someone else.
- If you need your employer to make changes to the way you work, ie reasonable adjustments (see page 14).

You may decide that you don't want to tell potential employers that you have Parkinson's.

This may be because:

- you don't feel comfortable telling people about your condition
- you believe your symptoms won't interfere with your ability to do the job
- you feel that, at this time, the fact that you have Parkinson's is irrelevant to your working life

On the other hand, you may decide you'd rather tell a potential employer about your condition.

This may be because:

- you prefer it when others know about your condition
- your symptoms are quite noticeable and you want to explain these at your interview
- you'd like to reassure your employer that you can do the job, perhaps with reasonable adjustments (if you think you need them)

Take some time to decide what you think is best for you, taking into consideration your symptoms, the type of job you are applying for and your personal preferences. You may wish to discuss it with someone you trust or speak to others with similar experiences.

### Be prepared

If you do choose to mention your Parkinson's on your application or at interview, be prepared for the response.

In Great Britain, an interviewer should accept what you have said and move on without asking you any further questions. This is because employers in Great Britain are not allowed to ask questions about health or disability before offering you a job.

In Northern Ireland potential employers are allowed to ask questions about your health, but they must be clear about what this information will be used for. For example, are they asking so they can consider what reasonable adjustments you may need?

## What is positive discrimination?

Positive discrimination is when one person is chosen over another for a job because of their age, disability, marital status, race, sex or sexual orientation.

Generally, this is unlawful except in the case of disability. Both the Equality Act and the Disability Discrimination Act allow employers to actively seek people with a disability for a role in certain circumstances.

The most common forms of positive discrimination are the following.

- The 'Two Ticks' or Disability Symbol. The Disability Symbol is awarded by Jobcentre Plus to employers who make a commitment to employ, keep and develop disabled employees. This includes a guarantee to interview a disabled person who can do the job. If you are looking for work you may want to look out

for employers who display this symbol in their adverts. This scheme is not run in Northern Ireland but there may be others. See the nidirect website [www.nidirect.gov.uk](http://www.nidirect.gov.uk) for details of positive discrimination schemes in Northern Ireland.

- Adverts for jobs that say that the employer wants someone with a particular type of disability. This is usually because the role is working with people with that disability, for example the Royal National Institute for the Blind might want to employ someone who has a visual impairment.



# WORKING WITH PARKINSON'S

If you are working when you are diagnosed or living with Parkinson's, you may be wondering what you should tell your employer about your condition.

This section looks at telling your employer and your colleagues about Parkinson's, what reasonable adjustments are and what to do if your employer does not fulfil its obligations to you.

## Should I tell my manager about my diagnosis?

This is up to you, though there may be some factors that influence your decision.

You don't have to tell your manager or anyone else at work about your Parkinson's unless:

- there is a health and safety risk (ie your condition means that either you or someone else may be at risk of harm)
- you need to change the way you work because of your symptoms.

In this case you will need to ask your employer for a reasonable adjustment under the Equality Act or Disability Discrimination Act in Northern Ireland. Your employer will need to know how your disability makes it difficult for you to do your job. For more on reasonable adjustments see page 14.

Unless you work in a small organisation without a human resources function, your manager doesn't normally need to know that you have Parkinson's. You can just say that you have a health condition and you need to change the way you work (if this is the case).

Your manager will probably ask you to speak to someone in the human resources department and you may be referred to an occupational health specialist or other medical adviser.

They will put a report together on how your condition affects your ability to do your job and what changes could be made to make sure

you can keep working or remove any disadvantages you may have at work because of your disability.

If you work for a large organisation, they may have their own occupational health specialists. Smaller businesses may send you to a GP.

The occupational health specialist or GP you're referred to will need to know your diagnosis and you should be asked to sign a consent form that lets them ask for reports from your own GP or specialist.

If you decide that you want to tell your manager about your condition you may find it helpful to give them some information about the condition, such as our leaflet *A quick introduction to Parkinson's*. You could also refer them to our website **[parkinsons.org.uk](http://parkinsons.org.uk)**

Remember that if you tell your manager about your condition, they must not tell anyone else without your consent, except in very limited circumstances.

For example, they may have to tell human resources or other managers in order to comply with their legal obligations to you, such as their duty to look after your health and safety and to make

reasonable adjustments under the Equality Act. If they do tell anyone else about your condition outside of these circumstances, they may be breaking the law.

This is because the Data Protection Act says that information about health is sensitive, personal data and may only usually be shared if you say so.

If you do inform your manager and/or human resources department about your condition, you may find it helpful to ask for more information about their policies related to employees with a long-term condition.

## Should I tell my colleagues about my condition?

It is entirely up to you whether you tell your colleagues about your condition. But the important thing to know is that you don't have to tell your colleagues if you don't want to.

Because you are under no obligation, you can take the time to decide what you think is best for you in terms of what, if anything, you tell your colleagues.

You may want to think about things like how your condition may affect you and your colleagues in the

workplace, how noticeable your symptoms are and what your relationship is like with the people you work with.

You may wish to discuss your decision with someone you trust outside of work or speak to others with similar experiences.

### **If I do want to tell my colleagues, what is the best way to do this?**

If you do decide to tell your colleagues about your condition, you may like to spend some time thinking about what you want to tell them and how you want to do this.

You may want to tell them about Parkinson's in detail or you may prefer to be less specific and just let them know you have a health condition.

You may find it helpful to talk to your manager about how to tell your workmates. For example, you can tell them yourself or ask your manager to do it for you.

Some employers run sessions, where an expert will come in and talk about a particular health issue to educate and inform employees.

You could discuss running a session on Parkinson's and decide whether

or not you would want to take part in this.

### **What are reasonable adjustments?**

If you have Parkinson's, you may have difficulties in relation to where you work.

These difficulties may put you at a substantial disadvantage compared to other employees without a disability. By law, your employer must help to overcome or lessen that disadvantage by making changes to parts of the premises or working arrangements. These changes are called 'reasonable adjustments'.

These may include the following.

- Making changes to the premises where you work (for example, steps or doors).
- Altering your job, which may involve giving some of your non-core work that is difficult for you to someone else, like the occasional need for travel or work at a different site.
- Moving you to another post or place of work (see page 28 for more on redeployment).

- A change in working hours.
- Working from home for some or all of the time, with the right equipment.
- Giving you training.
- Giving you modified equipment, such as computer adaptations, large button telephones or adjustable chairs.
- Making instructions and manuals easier to use.
- Using a reader or interpreter.
- Increasing supervision.
- Providing an automatic car if you need to drive at work.
- Arranging with a taxi firm to supply taxis that will be paid for by Access to Work.

This list doesn't cover everything, because what is reasonable and effective will be different for everyone. Alongside yourself, an occupational health adviser or an Access to Work assessor (see page 22) is best placed to identify what adjustments may help you.



## How do I make a request for reasonable adjustments?

If you are having problems doing your job or parts of your job, the first thing to do is talk to your manager.

An employer is only obligated to make reasonable adjustments if they know, or could reasonably be expected to know, that you have a disability. So you do need to tell them that you have a disability, but remember that you don't have to tell them you have Parkinson's if you don't want to.

Try to explain what part of your job is causing a problem and what that problem is. For example, you may have difficulties travelling to work on public transport during rush hour because you can't get a seat and find it difficult to stand for long periods of time. Or you may have problems using equipment such as a keyboard or computer because of movement difficulties.

You may also have some suggestions for changes that will help you. These could be starting and finishing later in the day, or speech to text software installed on your computer. These may have been adjustments that worked for you in a previous job.

Don't worry if you don't have any suggestions for what reasonable adjustments may help you. Your manager should arrange for you to have an assessment with an occupational health adviser to find out what your problems are and to make suggestions for how they can be solved.

## What if my manager doesn't know what to do, or does nothing?

If your manager does not do anything to make the reasonable adjustments you need, you will need to contact the human resources department.

You can also contact Access to Work (see page 22 for more information) and make an application for an assessment.

Take some time to think about what adjustments may help you, but remember that they have to be reasonable – ie something that your employer will be able to do. When considering whether it is reasonable to make a particular adjustment, your employer can take the following into account.

- Will the adjustment be effective in helping you to do your job?

“ I was diagnosed when I was 28. At the time, I was a staff nurse working full-time in a busy hospital environment. I have had to reduce my working hours twice since then and now I work part-time. I experience stiffness, lack of co-ordination and balance problems. I don't have the energy to run around like I used to.

I was quite nervous about telling my manager about my condition. I wasn't sure of my rights at the time and I felt vulnerable. But she was very supportive. I now meet her for a review every three months to discuss my condition and abilities at work.

I was quite upset that I had to reduce my hours. It made me realise that my symptoms were getting worse, and I don't feel I'm part of the team as much as I used to. I also worry about my three-monthly review. I don't want to leave the department I work in, because I love it.

But reducing my hours has helped me manage my symptoms better. And I'm very lucky that I get a lot of support from my colleagues. They notice when I'm struggling and encourage me to rest if I need to. I also have support from my friends and family, especially my husband.

I really feel like this condition is trying its hardest to bring me down, but I am strong. I want to keep working and stay positive, despite my condition. ”

**Kirstie, diagnosed in 2011**

- How practical is the adjustment? For example, is it possible for you to access a database from home or is there anyone to cover for you if you start work later in the day?
- What is the extent of any disruption caused? For example, what would the impact be in making changes to the building.
- What are the financial and other costs of the adjustment to the business? What is reasonable for a large employer may not be affordable for a small business.
- Is there any financial or other assistance to help make reasonable adjustments? Access to Work may make a contribution to the cost of some adjustments, such as equipment, but there may be other costs involved.

If your employer is a member of the Business Disability Forum ask your manager to look at the website or call the advice line for practical advice on what to do, as well as information on what the law states. See page 40 or details of the Forum.

## Can I use reasonable adjustments as and when I need them?

Because Parkinson's is a fluctuating condition, you may find it easier to manage your symptoms on some days more than others. If you do tell your employer about your condition, it may help to make sure they understand that this is a fundamental part of life with Parkinson's.

Depending on what you do and what your needs are, it may be possible for you to change the way you work only when you need to. For example, you could discuss the following with your employer.

- Working from home from time to time.
- Using taxis instead of public transport to take you to out-of-office meetings.
- Dialling into meetings rather than attending in person.
- Temporarily changing your duties to help you concentrate on those you can do (for example catching up on administrative tasks or desk-based work).

- Temporarily doing flexible hours to help you work around the times of day when you're feeling less able.

## What are Workplace Adjustment Agreements?

When you and your manager have agreed on some reasonable adjustments, it's a good idea to put them in writing. This is called a Tailored Adjustment Agreement or Workplace Adjustment Agreement.

The purpose of recording this agreement is to:

- make sure that you and your employer have an accurate record of what has been agreed

- reduce the need to rearrange your reasonable adjustments every time you change jobs, are relocated within the organisation or get a new manager
- provide you and your line manager with a basis for discussion about your reasonable adjustments at any future meetings, such as your regular catch-ups or one to ones. (You should regularly review your adjustments with your manager to make sure they are still working and to agree and make any necessary changes)



You can download a template agreement from the Business Disability Forum. See the more information and support section for contact details.

## Can I take time off for medical appointments or for treatments?

Yes. You can ask to take time off work for your medical appointments or treatment as part of your reasonable adjustment agreement.

Talk to your manager about how much time you think you need. If the appointments are for fixed times and you know well in advance, your employer should be able to allow you to take the time off you need.

Just be aware that your manager may do the following.

- Ask you to make up the time.
  - Allow you to take the time as unpaid leave (if you work for a small employer who can't afford to give you paid leave).
  - Ask if the appointments can be arranged for the beginning or the end of the day so that you can work for most of that day.
- Ask you to try to book appointments for days or times when you are not on the rota to work (if you work shifts).



## What if I need to take sick leave?

If you are too unwell to work you may need to take time off sick. Time off sick is unplanned. Under these circumstances you should follow your employer's usual procedure on reporting sickness.

This will include telling your employer immediately that you're not able to work. If you're off sick for more than seven days, you will need to arrange getting a doctor's 'fit note' to give to your employer.

If you are off sick due to your Parkinson's symptoms and haven't told your employer about your condition yet, you may feel it's best to do so before they receive a fit note or letter from your doctor.

## Am I entitled to any sick pay?

Each place of work will have a different policy on sick pay. But if you are off sick for more than four working days in a row (including non-working days) you may qualify for Statutory Sick Pay. This will be paid by your employer for up to 28 weeks.

You may qualify for more if your company has a sick pay scheme (or occupational scheme). Check your employment contract for details.

If you don't qualify for Statutory Sick Pay, you may be able to take holiday instead of sick leave.

There may also be other benefits you can claim whether you qualify for Statutory Sick Pay or not, such as Housing Benefit.

To find out more about what you may qualify for, call our confidential helpline **0808 800 0303** and speak to our benefits and employment adviser.

## What happens when I go back to work?

If you've taken some time off and your employer is aware of your disability, their policies may allow you to have a few days more for sick leave than other employees before they start attendance improvement procedures.

Some employers ask on their sickness certificate that you complete when you return to work if your absence was related to a disability.

If you want your employer to know that you have a disability or if you think you need to change the way in which you work (ie reasonable adjustments), you should say yes to this question.

This may mean that you have to see an occupational health adviser or other medical adviser who will ask you about your symptoms and the way they affect you at work.

If you've been on sick leave for more than a few days, your employer may ask you to see their

occupational health adviser or other medical adviser before your sick pay entitlement has expired.

If there is medical evidence that your Parkinson's means you are more likely to need more time off sick than other people, this is a good opportunity to agree on some reasonable adjustments to prevent you taking time off sick. For example, you may find it helps to work from home from time to time.

## Am I at risk for dismissal if I take long-term sick leave?

Employees who are off work sick for more than four weeks may be considered long-term sick.

As a last resort, employers can dismiss an employee who is long-term sick, but before they can do this they must do the following:

- consider if an employee can return to work, for example working flexibly or part-time, doing different or less stressful work (with training if necessary)
- consult with the employee about when they could return to work and if their health will improve

If you are dismissed without this being done, you should seek advice

immediately. See page 26 for more information on dismissals.

## What is Access to Work?

An Access to Work grant is money for practical support to people with a disability, such as a long-term health condition.

The Access to Work programme is administered by Jobcentre Plus or Jobs and Benefit Offices in Northern Ireland. It is there to provide help towards covering the costs of adjustments which otherwise would not be reasonable (eg they would be too expensive for your employer).

Your employer still has a duty to make reasonable adjustments under the Equality Act and the Disability Discrimination Act.

## What can Access to Work provide funding for?

Grants can provide funding for the following.

- A support worker if you need practical help either at work or getting to work (eg getting in and out of your car).
- Adaptations to a vehicle, or help towards taxi fares or other transport costs if you cannot use public transport to get to work.

- Any equipment (or alterations to existing equipment) that is necessary because of Parkinson's (eg voice to text software or an adapted chair).
- Alterations to premises or a working environment, eg making doors easier to open.

## How do I apply?

Applications for Access to Work must be made by the person with the disability on the application form.

If you're in England, Scotland or Wales contact your regional Access to Work centre for more information or to apply.

Contact details can be found in the more information and support section. An adviser will then contact you and your line manager to arrange for an appraisal of your needs.

You can also visit [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work) to find out more about the scheme.

If you're in Northern Ireland, you should contact an Employment Service Adviser in your local Jobs and Benefits office or JobCentre. You can find out where this is by calling the free phone number **0800 353 530**.

You can also visit [www.nidirect.gov.uk](http://www.nidirect.gov.uk) to find out more about the scheme.



## What if I think my employer is discriminating against me?

This information applies whether you are a person with Parkinson's or if you care for someone with the condition.

If you feel you are being treated unfairly in the workplace, the first thing to do is talk to your line manager. Ask for a meeting and talk to them about what has been happening (for example, you may feel you are being discriminated against because the reasonable adjustments you requested haven't been made or you feel a colleague is treating you unfairly).

If your line manager is the problem, then you need to talk to their manager or the human resources manager. It's best to start with an informal discussion.

Your employer may simply not realise what difficulties you may be having or be aware of their legal obligations. If you explain what you need they may be willing to make the necessary changes.

If you are uncomfortable about talking to your employer alone there are things you can do. If you are a member of a union, you can ask a trade union representative to go with you or you can ask if you

can bring a colleague of your choice with you to the meeting. You can also ask your employer to allow a family member or trusted friend to be there with you for moral support.

If, after the informal meeting, you are still unhappy, you should make a formal complaint or grievance. Your staff handbook should tell you the process for doing this, or you should ask for guidance from the human resources department on the employer's policies.

You will also need to find out more about your legal rights. Your trade union, the Equality and Human Rights Commission (EHRC), the Citizens Advice Bureau or the Equality Commission for Northern Ireland should be able to provide you with advice. See the More information and support section for contact details.

“ I was diagnosed with Parkinson’s when I was 53. At the time I was working as a biomedical scientist. Even though this was essentially an academic position, my condition still had an affect on my working life. I had to write clearly, use computers and stay alert.

Parkinson’s doesn’t hit you all of a sudden. Instead, it creeps up on you. I started finding it harder and harder to do even the simplest tasks. I’ve always been proud of my work, but was finding it increasingly difficult. Because of this I became more tired.

When I told my employer they let me go. Because I was effectively self-employed, they had no obligations towards me. I always planned to retire early, but obviously not like this. My wife and I decided not to have children, so we’d already made a real effort to pay off the mortgage, avoid debt and save money.

Financially, we are OK for now – my lovely wife is still working – but we do worry about our future. I’ve planned all that I can. I’ve paid off my mortgage, am using a second-hand car and generally cut back on everything I can.

It’s hard to give advice as everyone’s circumstances are different. But it’s important not to let things slide. Get your finances, pension and benefits in order. Everyone says ‘stay positive’, but give yourself a break to be miserable some days – the key phrase here being ‘some days!’ ”

**Chris, diagnosed in 2010**

# ENDING WORK

## What can I do if I believe I am being dismissed because of my condition?

If you are dismissed because of your disability or because your employer doesn't want to make reasonable adjustments you may be able to make a claim for disability discrimination and/or unfair dismissal.

You must find out what rights you have to bring a claim and what you should do next as soon as possible because strict time limits apply to making claims to the employment tribunal.

If you have been given a warning about your performance or conduct at work, you may be at risk of dismissal and should seek advice immediately.

This can be from your Trade Union if you are a member, your local Citizens Advice Bureau or Law Centre or from the Disability Law Service. See page 39 for contact details.

## What is redundancy?

The information on redundancy applies whether you are a person with Parkinson's or if you care for someone with the condition.

If all the correct procedures are followed, redundancy is a lawful and fair way of dismissing employees that the employer no longer has work for. Your employer can only lawfully make you redundant if:

- the business as a whole is closing
- a particular branch, office or workplace is closing
- fewer employees are needed to do particular work
- the job you are doing no longer exists

Remember that any periods of disability-related absence should be ignored for the purpose of selecting an employee for redundancy.

## Am I entitled to redundancy pay?

If you have worked for the same employer for two years or more you will be able to claim statutory redundancy pay. The amount will depend on your age, salary and length of service and your employer must give you a statement setting out how your redundancy pay has been calculated.

Currently you are entitled to:

- half a week's pay for each year of employment during which you were aged 21 or under
- one week's pay for each year of employment in which you were aged between 22 and 40
- one and a half week's pay for each year of employment in which you were aged 41 or over

The maximum number of years that can be taken into account is 20 and a week's pay is subject to an upper limit that is set annually.

## When are dismissals not redundancies?

If you think that the real reason that you have been selected for redundancy is because of your condition or because you care for

someone with Parkinson's then you may be able to make a claim for unfair dismissal and disability discrimination.

You need to seek legal advice as soon as possible, as strict time limits apply for making claims to the Employment Tribunal or the Industrial Tribunal in Northern Ireland. You can get help from your Trade Union if you are a member or from your local Citizens Advice Bureau, Law Centre or from the Disability Law Service (see page 39 for details).

If your job still needs to be done but you are not able to do the work for any reason, including because of your disability, this is not a redundancy. If you resign or are dismissed for any reason this is not because of redundancy, even if you don't have another job to go to. See advice in the section on redeployment on page 28.

An employee whose contract is terminated by the employer because they are no longer able to do their job or a suitable alternative job, even with reasonable adjustments, is also not redundant if the work they used to do still needs to be done by another employee.

## Can I ask for redeployment as a reasonable adjustment?

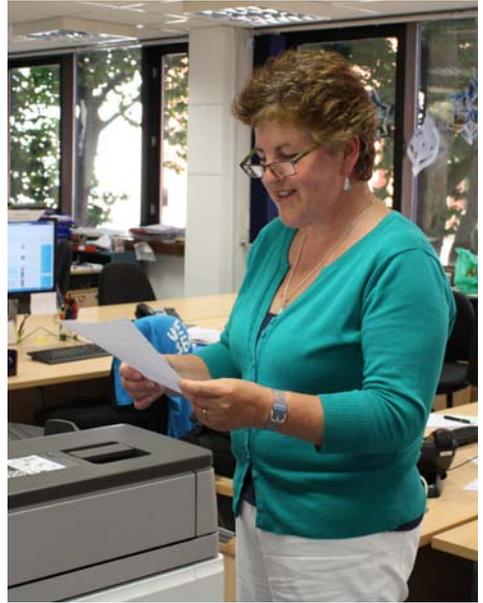
If there are no reasonable adjustments that would mean you could do your current job, your employers must look for suitable alternative jobs that you can be transferred to.

Remember that the job might be suitable if other reasonable adjustments are made (for example, changing hours or location, providing equipment).

It is not enough for your employer to simply let you know about internal jobs and suggest that you apply. Disabled employees who need to be redeployed as a reasonable adjustment should not have to take part in competitive interviews for vacant jobs, if they are qualified to do them, or would be with a reasonable amount of training and support.

This is redeployment as a reasonable adjustment under the Equality Act and is different to redeployment of an employee, disabled or not, who is at risk of being made redundant.

If you can't do your job, even with reasonable adjustments, and there is no other suitable job in the



organisation for you, your employer can terminate your contract.

This may be a fair dismissal and as you are not redundant you will not be entitled to a redundancy payment. This is because your job still needs to be done and your employer will have to find someone else to do your job.

## When should I retire?

Some people with Parkinson's may start thinking about giving up work completely before reaching state retirement age.

This may be because they feel that working with Parkinson's is becoming too difficult and they

want to concentrate on other aspects of their life.

If you are thinking about retiring it may help to consider the following.

- Don't rush into a decision. If you're finding it difficult to manage your symptoms, you may just need changes to your Parkinson's drugs – and take some time to adjust to this.
- Speak to your employers and professional or trade organisations to make sure you're leaving on the right terms at the best time. Some companies encourage their employees to attend training courses on preparing for retirement.
- Look carefully at your finances, including your pension, benefits and savings. Keep in mind that any benefits you get from work will end. It may be helpful to seek advice from an independent financial adviser.
- Call our helpline on **0808 800 0303** or speak to your local Citizens Advice Bureau or local welfare benefits service.
- Think about how stopping work will affect you emotionally and practically.

If you do decide to retire, it may take time to adjust to life without work. Talking to someone may help. This may be a family member, trusted friend or others who have gone through retirement. A counsellor can also help.

## What are ill-health retirement and Permanent Health Insurance (PHI) schemes?

If you have been paying into a pension scheme you may be able to take early ill health retirement. Whether or not this is possible will depend on the terms of your pension scheme. If you retire early but are still medically fit for work, the amount you get may be lower.

If you have ill health or disability insurance you may be able to make a claim on that policy. Remember, however, that to make a claim on such a permanent ill health or PHI scheme you need to be employed.

If your contract of employment is terminated, you will not be able to claim on your insurance policy. If this happens you should seek legal advice as you may have a claim for breach of contract.

To make sure you are aware of all your options when getting your pension, it is advisable to talk to an independent financial adviser.

“ At the time of my diagnosis, I was working in risk management in quite a senior position. I loved my job and for three years or so I continued to work with no problems. My boss and colleagues were aware of my condition and everyone was very supportive.

After a while, I took a sideways step, which worked well for about 18 months, but again, I started to feel I wasn't really coping as well as I always had.

After reviewing our finances, my husband and I decided that we were financially stable enough for me to retire in the next year. I had never planned to retire early and didn't want to stop working at 56, but at least I had some control over when I stopped working.

Unfortunately, before we got to that time, my organisation started making redundancies. I was lucky – I negotiated a reasonable redundancy package, but I was still upset that I was finishing work earlier than anticipated.

I found this incredibly difficult because I'd lost the time I needed to prepare for such a big change. I had worked for 35 years and it was an important part of my life – integral to my self-esteem. It was very hard to cope with that loss on top of the other things Parkinson's can take away.

But if you have Parkinson's, it's important not to dwell on what you've lost or what you may lose in time. Get the support you need from family or friends to help you find something new to focus on, whatever that may be. ”

**Anna, diagnosed in 2006**

# WORK AND CARING FOR SOMEONE WITH PARKINSON'S

You may be working as well as caring for someone with Parkinson's. Paid work can provide financial independence and money to help with caring, a break from caring, social networks and friendships, self-esteem and a better pension, but combining your responsibilities has its own challenges.

Your employment needs should be taken into account in any assessment from your local authority.

**Find out more:** see our booklet *The carer's guide* for more information on carer's assessments.

## Are carers protected against discrimination in the workplace?

If you care for someone with Parkinson's you are protected from being discriminated against or harassed at work because of your link to someone with a disability, such as a long-term condition.

This means that as a carer you should not be treated less favourably than another employee who isn't a carer, and should not be denied the flexibility you are legally entitled to. Any offensive language about your association with a person with Parkinson's should also not be tolerated.

There are things you can do if you believe you are being discriminated against in the workplace. See page 24 for details.

## Should I tell my employer that I'm a carer?

You do not have to tell your employer you are a carer but it may help if they are aware if you need to take time off to look after the person you care for. Checking your employee handbook or talking to the human resources department will also help you find out what support may be available to you at work.

You might make this decision depending on whether your

employer has a policy to support carers, or whether they'd be open to exploring ways to support you. Find out what's available before you approach your manager.

As a working carer, you are likely to need a range of support – such as access to a telephone to check on the person you care for.

An understanding employer can make all the difference to whether or not you feel you can seek support.

Possible support options include:

- leave arrangements (paid or unpaid at your employer's discretion, to cover intensive periods of care)
- an employee assistance programme, if your workplace has one. This is a workplace-focused programme designed to resolve any personal or work-related problems you have that may affect your ability to do your job
- access to advice and information, for example on a staff website or carers' network

## Should I tell my colleagues?

This is up to you, so take some time to consider what you think is best. Colleagues can be very supportive, and it may help to talk with someone you can trust at work. You may find that other colleagues are also carers. Together, you may be able to talk to your employer about ways you could be supported in juggling your job and caring.

## Do I have the right to request flexible working hours?

You don't have the right to ask for reasonable adjustments (see page 14) but you may have a statutory (legal) right to ask your employer if you can work flexibly. This may mean changing your hours or working from home.

Your right to make this request will depend on your relationship to the person with Parkinson's and how long you have been working at your company.

Your employer must give serious consideration to your request but they can refuse if there are good business reasons for doing so. Requests made under the statutory scheme will, if agreed, become permanent changes to your terms and conditions.

To find out more about who has the statutory right to ask for flexible working visit [www.gov.uk/flexible-working](http://www.gov.uk/flexible-working)

Whether or not you meet the criteria for making a statutory request for work flexibility, remember that there is nothing stopping you from making an informal request to your employer.

This may also be appropriate if you need a temporary change to your terms and conditions.

### Where can I get support?

If you are a member of a trade union, ask them for help. A local, or regional, union representative may

be able to negotiate with your employer on your behalf and attend meetings with you.

If you are not in a union, you have the right to have a colleague attend certain types of meeting with you.

Call our helpline adviser for employment and benefits on **0808 800 0303** to discuss your employment rights.

### Can I get time off in an emergency?

The Employment Rights Act 1996 allows employees to take a 'reasonable' amount of time off work to deal with an emergency involving a dependant.



A dependant could be one of the following.

- husband or wife
- partner
- child
- parent
- friend or family member who lives with you but doesn't pay rent
- someone who relies on you to care for them (for example, an elderly neighbour)

You should not be victimised or dismissed by your employer for using this right. It is at the employer's discretion whether the leave is paid or unpaid. Situations where leave might be taken include:

- an acute emergency, such as a fall, that results in an ambulance visit
- a disruption or breakdown in care arrangements
- if the person you care for falls ill
- to make longer-term arrangements for a dependant

You should also find out how unpaid time off might affect your work rights, pension and working tax credit eligibility.

## Should I stop doing paid work?

If you are thinking of leaving work altogether, think about whether it's right for you:

- Do you really want to leave, or is there an alternative?
- Could you manage with less money (and any effect on an occupational pension)?
- How do you feel about the potential loss of independence, social contact and valuable skills?

Employers are keen to keep skilled, experienced and committed staff, so they may be keen to consider solutions. These could include:

- paid or unpaid leave that allows you to think about long-term options
- part-time working or job sharing
- working from home

If you decide you have to leave work, think about options other than resigning, such as:

- a career break
- voluntary redundancy
- early retirement

It may take some time to get used to the new situation but there should be benefits, such as more leisure time with loved ones.

See page 26 for more information on retirement and redundancy.

### What about my finances?

If you are considering leaving work to spend more time caring for a loved one, you may be concerned about your finances. But there are things you can do to ease any worries, such as making sure you are claiming all the benefits you are entitled to.

**Find out more:** see our booklet *The carers guide*.



“

I decided to go back to work a year after my husband was diagnosed. I'd always planned to work again after having time off to study full time, but now it was even more important. We needed the money and work helps me stay strong and focus on something other than Parkinson's.

I found work as a temp, but have now been with the same employer for nearly 12 years. I told them in my interview about Bob's condition. I wanted to be upfront from the beginning and not put any more pressure on myself. It's an administration role, but I am also involved with our HR department and wellbeing team. I use my caring experiences to provide support to the teams on carer's needs.

My employer offers flexible hours and everyone is very understanding when I need time off, though I try not to take too much. My organisation also provides access to a counselling service that has been a blessing to me at times.

To other working carers I would encourage you not to keep things to yourself. If times are difficult, tell your employer so they can offer you support. Also, try to look after yourself at work and take time out for yourself – have the odd lunch with friends, go to the gym or go for a walk. Look after yourself. ”

**Elizabeth, whose husband has Parkinson's**

# MORE INFORMATION AND SUPPORT

## Information and support from Parkinson's UK

If you have any concerns about how Parkinson's may affect your working life, we are here to help. Ring our helpline on **0808 800 0303** to speak to our benefits and employment adviser.

Our helpline also provides general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our local information and support workers, who provide one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at **parkinsons.org.uk/localtoyou**. You can find details of our local groups and your nearest meeting at **parkinsons.org.uk/localgroups**. You can also visit **parkinsons.org.uk/forum** to speak with other people in a similar situation on our online discussion forum.

## Information and guidance on the Equality Act 2010

The Government Equalities Office has information and guidance on the Equality Act 2010 on its website.

**[www.gov.uk/equality-act-2010-guidance](http://www.gov.uk/equality-act-2010-guidance)**

## Information and guidance on the Disability Discrimination Act 1995 in Northern Ireland

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

## Equality Advisory Support Service (EASS)

The EASS helpline can provide information, advice and support on discrimination and human rights issues to people in England, Scotland and Wales.

This can include advice about the Equality Act 2010 and how this applies you, what options you have in regards to resolving any issues at work and assisting you in finding local sources of support. The EASS does not provide legal advice.

**0808 800 0082**

Textphone: **0808 800 0084**

**[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)**

## The Equality and Human Rights Commission

**[www.equalityhumanrights.com](http://www.equalityhumanrights.com)**

## Equality Commission for Northern Ireland

**028 90 500 600**

Textphone **028 90 500 589**

**[information@equalityni.org](mailto:information@equalityni.org)**

**[www.equalityni.org](http://www.equalityni.org)**

## Access to Work (For England, Scotland and Wales)

London (for South East England and East England)

**[atwsu.london@dpw.gsi.gov.uk](mailto:atwsu.london@dpw.gsi.gov.uk)**

**020 8426 3110**

Textphone **020 8426 3133**

Cardiff (for South West England, Wales, West Midlands and East Midlands)

**[atwsu.cardiff@dpw.gsi.gov.uk](mailto:atwsu.cardiff@dpw.gsi.gov.uk)**

**02920 423 291**

Textphone **02920 644 886**

Glasgow (for Scotland, North West England, North East England, Yorkshire and Humberside)

**[atwsu.glasgow@dpw.gsi.gov.uk](mailto:atwsu.glasgow@dpw.gsi.gov.uk)**

**0141 950 5327**

Textphone: **0845 6025850**

## Advisory, Conciliation and Arbitration Service (ACAS)

This organisation provides information for both employers and employees who are involved in an employment dispute or are seeking

information on employment rights and rules.

Helpline **08457 47 47 47**

Text Relay **18001 08457 47 47 47**

**www.acas.org.uk**

## Community Legal Advice

Community Legal Advice is a free and confidential advice service in England and Wales paid for by legal aid.

**0845 345 43 45**

To find legal advisers or solicitors near you call the helpline or visit **<http://find-legal-advice.justice.gov.uk/>**

## Citizens Advice

### England

**0844 411 1444**

**www.citizensadvice.org.uk**

### Wales

**0844 477 2020**

### Northern Ireland

**www.citizensadvice.co.uk**

### Scotland

**www.cas.org.uk**

### Online advice guide

**www.adviceguide.org.uk**

## Disability Action (Northern Ireland)

This organisation works to ensure that people with disabilities attain their full rights as citizens, by supporting inclusion, influencing government policy and changing attitudes in partnership with disabled people.

**028 9029 7880**

Textphone **028 9029 7882**

**www.disabilityaction.org**

## Disability Law Service

This organisation provides specialist legal advice for disabled people, their families and carers.

**020 7791 9800**

**www.dls.org.uk**

## Disability Rights UK

Provides people with disabilities with information on their rights and benefits, including its Disability Rights Handbook.

**020 7250 3222**

**enquiries@disabilityrightsuk.org**

**www.disabilityrightsuk.org**

## Law Centres

Law Centres are not-for-profit legal practices providing free legal advice and representation to disadvantaged people.

To find the nearest Law Centre in England, Wales and Northern Ireland visit

[www.lawcentres.org.uk](http://www.lawcentres.org.uk)

To find the nearest Law Centre in Scotland visit [www.](http://www.scotlawcentres.blogspot.co.uk)

[scotlawcentres.blogspot.co.uk](http://www.scotlawcentres.blogspot.co.uk)

## For Employers

### Business Disability Forum

This is a not-for-profit member organisation providing information to employers about doing business with and employing disabled people.

**020 7403 3020**

Textphone: **020 7403 0040**

**enquiries@**

**businessdisabilityforum.org.uk**

**www.efd.org.uk**

## For Carers

### Carers UK

CarersLine **0808 808 7777**

**www.carersuk.org**

### Cynhalwyr Cymru

**02920 811 370**

**www.carersuk.org/wales**

### Carers Northern Ireland

**02890 439 843**

**www.carersuk.org/northernireland**

### Carers Scotland

**0141 445 3070**

**www.carersuk.org/scotland**

## Employers for Carers

Employers for Carers is a website set up by employers for employers, which provides practical advice on supporting carers within their workforce. Visit **www.employersforcarers.org**

## Employment and Parkinson's (2013)

If you have comments or suggestions about this booklet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to:

**Resources and Diversity, Parkinson's UK, 215 Vauxhall Bridge Road  
London SW1V 1EJ.**

Or you can email us at [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thanks!

### Please tick...

- I have Parkinson's. When were you diagnosed? .....
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this booklet from?

### Please tick...

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other .....

How useful have you found this booklet?

(1 is not useful, 4 is very useful)  1  2  3  4

Have you found the publication easy to read/use?  Yes  No



Continued over the page

What aspects did you find most helpful? .....

Were you looking for any information that wasn't covered? .....

Do you have any other comments? .....

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group (people affected by Parkinson's who give us feedback on new and updated resources), please complete the details below and we'll be in touch.

- Membership                       Information review group

Name .....

Address .....

Telephone .....

Email .....

What is your ethnic background?

**Please tick...**

- Asian or Asian British     Black or Black British     Chinese     Mixed  
 White British     White other     Other (please specify) .....



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

**Bela Gor, Legal Director, Business Disability Forum**

**Deborah West, Consultant Solicitor, Wilsons Solicitors LLP**

**Stephen O'Brien, Advisory Officer (Benefits and Employment),  
Parkinson's UK**

**Laura Bowey, Head of Information and Support, Parkinson's UK**

**Karen Bown, Information and Support Worker, Parkinson's UK**

**Pam Davies, HR Business Partner, Parkinson's UK**

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

All of the photographs in this booklet feature people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's and Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

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.

References for this booklet can be found in the Microsoft Word version at [parkinsons.org.uk/publications](https://parkinsons.org.uk/publications)

**How to order our resources**

**0845 121 2354**

**resources@parkinsons.org.uk**

Download them from our website at [parkinsons.org.uk/publications](https://parkinsons.org.uk/publications)

**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 **020 7932 1303** or visit our website at [parkinsons.org.uk/support](https://parkinsons.org.uk/support). Thank you.

## 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

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

Monday to Friday 9am–8pm, Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

**hello@parkinsons.org.uk**

**parkinsons.org.uk**

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

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