

# WORK 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 how this might affect your work.

Whatever your circumstances, this information is 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 after reading this information you have specific 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.

If you're an employer or you manage someone with Parkinson's, we have separate information for you, which you can find at **[parkinsons.org.uk/employers](https://parkinsons.org.uk/employers)**

## Disclaimer

We've made every effort to make sure the information is correct at the time of publishing. But Parkinson's UK cannot take responsibility for the accuracy, 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.

## Contents

<b>How will Parkinson's affect my working life?</b> .....	6
How am I protected against discrimination in the workplace? .....	6
Will I still be protected during periods when I'm feeling fine? .....	7
<b>Reasonable adjustments</b> .....	8
How do I ask for reasonable adjustments? .....	8
What if my manager doesn't know what to do, or does nothing? .....	9
Can I use reasonable adjustments as and when I need them? .....	10
What are Workplace Adjustment Agreements? .....	10
<b>Looking for a job when you have Parkinson's</b> .....	12
What type of work is best for me? .....	12
Self-employment .....	12
Volunteering .....	13
Do I have to tell potential employers that I have Parkinson's? .....	13
Deciding whether to tell a potential employer about Parkinson's .....	14
What is positive discrimination? .....	15
<b>Working with Parkinson's</b> .....	17
Should I tell my manager about my diagnosis? .....	17
Should I tell my colleagues about my condition? .....	18
If I do want to tell my colleagues, what is the best way to do this? .....	19
Access to work grants .....	19
What can Access to Work provide funding for? .....	20
How do I apply? .....	20

<b>Taking time off work</b> .....	21
Can I take time off for medical appointments or for treatments?....	21
What if I need to take sick leave? .....	21
Am I entitled to any sick pay? .....	21
Am I at risk of dismissal if I take long-term sick leave? .....	22
 <b>Problems at work</b> .....	 23
What if I think my employer is discriminating against me? .....	23
What if I believe I am being dismissed because of my condition? ....	24
 <b>Ending work</b> .....	 26
When should I stop working? .....	26
Can I ask for redeployment? .....	27
What are ill-health retirement and Permanent Health Insurance (PHI) schemes? .....	27
 <b>Work and caring for someone with Parkinson's</b> .....	 28
Are carers protected against discrimination in the workplace? .....	28
Should I tell my employer that I'm a carer? .....	28
Should I tell my colleagues? .....	30
Do I have the right to ask for flexible working hours?.....	30
Where can I get support? .....	30
Can I get time off in an emergency?.....	31
Should I stop doing paid work? .....	31
What about my finances? .....	32
 <b>More information and support</b> .....	 33

“ I’d been working for my employer for 6 years at the time of diagnosis. I had no idea how the condition would affect me or how it would progress. Work plays a major part of my life and to lose my job would affect me both psychologically and financially.

I think the most important thing for my employer to understand is that I can still work and want to continue to work as long as my condition allows.

I felt open discussion was the best option so that staff can ask me any questions regarding Parkinson’s without embarrassment. Everyone has fortunately been extremely supportive and this has made a tremendous difference to my coping with Parkinson’s in the workplace.

I believe it is important that I am totally honest with my employer about how my condition affects me and my ability to do the job role.

Senior staff have made it clear their intention is to allow me to stay in employment as long as I wish and support me in this aim. This support has given me the confidence to carry on working and removes any major worries I had when first diagnosed. ”

**Peter**

# HOW WILL 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. Work can be fulfilling and give us a sense of purpose.

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

Sometimes, you may need to make changes to your working life. This could be something relatively simple like reducing your hours, or it might be something more significant like changing career or taking early retirement.

The most important thing is to stay as informed as you can about your rights in the workplace, and use all the support available to you.

## How am I protected against discrimination in the workplace?

Having Parkinson's means you are likely to meet the statutory (legal) definition of being disabled under the Equality Act, or the Disability Discrimination Act in Northern Ireland.

This means that it is against the law for an employer to discriminate against you because of your Parkinson's.

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, and are explained more in the next section.

## 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're still protected even when your symptoms are not affecting your ability to carry out 'normal' day-to-day activities.

These activities may include:

- walking
- reading and writing
- carrying or moving things
- concentrating and learning
- having a conversation or using the telephone



# REASONABLE ADJUSTMENTS

Some people with Parkinson's may find it more difficult to carry out their work, compared to employees without a disability. By law, an employer must help an employee with a condition like Parkinson's to overcome any problems they have by making changes to working arrangements. These changes are called 'reasonable adjustments'.

Reasonable adjustments may include:

- making changes to the building you work in
- making changes to your role
- changing or offering more flexibility with your working hours
- offering you training
- modifying equipment you use, such as computer adaptations, large button telephones or adjustable chairs

This list doesn't cover everything, because what is reasonable and effective will be different for everyone and will depend on the circumstances. You may have your own suggestions on what might be helpful for you.

## How do I ask for reasonable adjustments?

If you're having problems doing your job or parts of your job, the first thing to do is to talk to your manager. If you need adjustments then you will need to tell them that you have a disability, but you don't have to tell them you have Parkinson's if you don't want to.

Try to explain which part of your job is causing you 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 hard to stand for long periods of time. Or you may have problems using a computer keyboard because of a tremor.



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

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

If your manager doesn't do anything to make the reasonable adjustments you need, you should contact the human resources department and explain your situation.

You can also contact the Access to Work scheme and apply for a grant. (See 'Working with Parkinson's' section).

Take some time to think about what adjustments may help you, but remember that they have to be reasonable and something that your employer is able to do.

When considering whether it is reasonable to make a particular adjustment, your employer should take the following into account:

- Will the adjustment help you to do your job?
- 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 will the effect of the adjustment be? For example, what would the impact be in making changes to the building?
- How much will the changes cost the business, financially or otherwise? The type and size of your employer will be taken into account – what is reasonable for a large employer may not be affordable for a small business.
- Would the changes be disruptive to your employer's business?
- Is there any financial or other assistance available to help make reasonable adjustments? The Access to Work scheme may make a contribution to the cost of some adjustments.

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 says. You can find details of the Forum in the 'More information and support' section.

## 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 decide to tell your employer about your condition, it may help to make sure they understand that this is a big part of life with Parkinson's.

Depending on what you do and what your needs are, it may be possible for you to temporarily change the way you work when you are struggling. 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.
- Using teleconference or video calls rather than going to meetings in person.
- Temporarily changing your duties so that you concentrate on the things 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 often referred to as 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
- make it easier to continue your reasonable adjustments if you change jobs, move to a new location in the organisation or get a new manager
- give you and your line manager a chance to discuss 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)

“ I worked as a manager of bingo clubs around the country for over 20 years. I was responsible for every aspect of the business, from accounting and marketing to security and health and safety. I was extremely tired all of the time and couldn't cope with the high levels of stress that the job brought. I became increasingly depressed.

My chairman realised that I could not continue with the stress and physical exertion required in the job, and helped me find a new role with the industry trade association which proved much less stressful and much less physically demanding. Doing so meant I had much more energy and mental positivity.”

**Jason**

# LOOKING FOR A JOB WHEN YOU HAVE PARKINSON'S

## What type of work is best for me?

There are different options you can consider, including full-time and part-time work.

Before deciding what you want to do, you may find it helpful to think about:

- how your Parkinson's symptoms affect you. Would doing simpler tasks be better? It might be possible for you to change roles or level of responsibility in your work
- travel and mobility. How easy is it for you to travel to and from work? Think about whether you need to travel to other locations or offices
- your finances, including any pensions and savings you have. Knowing where you stand financially alongside what you think is best for your health will help you decide what type of work is best for you

- how many hours you feel you're able to work

## Self-employment

You may consider self-employment, which may give you some flexibility in terms of what you do and how.

There are certain things you need to think about if you are looking into self-employment. These include not necessarily having a regular income and having to arrange your own sick pay.

If you're thinking of becoming self-employed but aren't sure what you could do, you could consider something which uses your experience or skills, or something which you have previously done as a hobby.

You may want to set up a business as a trader, in a partnership or as a company. How you register and run the business will depend on how you set it up.

You can find information on setting up your own business and becoming self-employed at [www.gov.uk/set-up-business](http://www.gov.uk/set-up-business)

## Volunteering

Volunteering is a good alternative to paid work. Voluntary work can allow you to stay active, share your skills and meet new people, but have a lot more flexibility in terms of your working times. You could think about the things you enjoy doing or would be interested in trying.

Remember that you are allowed to do voluntary work while claiming some benefits. Sometimes the organisation you volunteer for will pay expenses, like travel fares.

There's lots of volunteering opportunities available across the UK, including with Parkinson's UK. Visit [parkinsons.org.uk/volunteering](http://parkinsons.org.uk/volunteering)

You can also find details of other volunteering organisations in the 'More information and support' section.

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

If you're looking for a job you may be wondering about whether you

need to tell a possible employer about your condition.

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 questions about your health for certain purposes, such as in the examples below.

- 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 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 they are processed separately from 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 scaffolder 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.

In Northern Ireland:

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.

However, 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 be only one of a number of factors that an employer should consider before reaching their final decision about who to hire.

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

## Deciding whether to tell a potential employer about Parkinson's

Generally speaking, it's up to you whether you tell a potential employer about your condition. Otherwise, the only time you would need to tell them is if:

- you think your Parkinson's may cause a health and safety risk either to you or to someone else
- you would need your employer to make changes to the way you work (reasonable adjustments)
- you live in Northern Ireland and your employer asks you to complete a pre-employment health questionnaire

You may decide that you don't want to tell a potential employer 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 affect your ability to do the job
- you feel that, at this time, the fact that you have Parkinson's doesn't make a difference 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. You could think about 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 others with similar experiences.

## What is positive discrimination?

Positive discrimination is when one person is treated more favourably than another because of a 'protected characteristic'. Protected characteristics are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, sex or sexual orientation.

Generally, positive discrimination 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 and treat them more favourably than a non-disabled person in certain circumstances.

The most common form of positive discrimination is when a job advert says that the employer wants someone with a particular type of disability. This is usually because the role is working with people with that disability and their personal experience is necessary. For example, the Royal National Institute for the Blind might want to employ someone who has a visual impairment for a specific role.





# WORKING WITH PARKINSON'S

## Should I tell my manager about my diagnosis?

This is up to you, but there are a few things to think about first.

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

- it may cause a health and safety risk either to you or to someone else
- 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. Although you won't need to tell your employer what your condition is, they will need to know how your disability makes it difficult for you to do your job

If you do not tell your employer about your symptoms, they will not be under a duty to offer you reasonable adjustments.

Unless you work in a small organisation without a human resources department, your manager doesn't normally need to know that you have Parkinson's specifically, if you do not feel comfortable telling them. 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 or someone in the human resources department should arrange for you to have an appointment with an occupational health specialist or other medical adviser. Occupational health specialists can work with you to find out what the impact of your work is on your health, and make sure you are fit for the work you do. 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.

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 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 Parkinson's. We have lots of information on our website, including specific information for employers about Parkinson's, that you may like to direct them to. Find out more at [parkinsons.org.uk/employers](https://parkinsons.org.uk/employers)

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 the human resources department or other managers to meet the terms of 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 or Disability Discrimination 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 be shared if you say so.

If you do let your manager or the human resources department know 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's entirely up to you whether you tell your colleagues about your Parkinson's. But the important thing to know is that you don't have to tell your colleagues if you don't want to.

You can take time to decide what you think is best for you in terms of what, if anything, you tell them. 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 education 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.

Parkinson's UK offers free awareness sessions for workplaces who employ someone with the condition. The aim is to give staff

“ I feel it is essential that everyone in the workplace, where there is an employee with Parkinson's, is educated. This means making sure everyone is aware of the symptoms and the knock-on effects these symptoms have on the person with the condition. Ideally, the employee who has Parkinson's should do the educating. They are certainly the one that knows.”

**Diane**

a better understanding of Parkinson's and the ways they can support colleagues (or customers) with the condition. You can find more at [parkinsons.org.uk/get-involved/parkinsons-your-workplace](https://parkinsons.org.uk/get-involved/parkinsons-your-workplace)

### **Access to Work grants**

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

Jobcentre Plus, or Jobs and Benefit Offices in Northern Ireland, administer the Access to Work programme. It is there to provide help towards covering the costs of adjustments which would be unreasonable to expect an employer to make, because they are too expensive or impractical. 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?

- A support worker if you need practical help either at work or getting to work, such as 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, such as voice-to-text software or an adapted chair
- Alterations to buildings, offices or a working environment, such as making doors easier to open

## How do I apply?

Applications for Access to Work grants must be made by the person with the disability.

If you're in England, Scotland or Wales, 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 freephone number **0800 353 530**. You can also visit [www.nidirect.gov.uk](http://www.nidirect.gov.uk) to find out more about the scheme.

# TAKING TIME OFF WORK

## 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. Whether your employer agrees will depend upon whether the time off is reasonable in the circumstances.

Talk to your manager about how much time you think you need. If you know when your appointment is in advance, your employer should be able to allow you to take this time off.

## What if I need to take sick leave?

If you are not well enough to work you may need to take time off sick. You should follow your employer's usual procedure for letting them know. 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 for statutory sick pay purposes. 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 get 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 sick for more than four 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.

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, call our confidential helpline on **0808 800 0303** and speak to our benefits and employment adviser.

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

Being off work sick for more than four weeks may mean that you are considered to be long-term sick. As a last resort, employers can dismiss you if you are long-term sick, but before they can do this they must:

- consider if you can return to work with some changes, such as working flexible hours or part-time, or doing different or less stressful work (with training if necessary)
- ask you about when you could return to work and if your health will improve
- follow a fair procedure
- take medical advice



# PROBLEMS AT WORK

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

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 asked for haven't been made, or you feel a colleague is treating you unfairly.

If your line manager is the problem, 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 are having or be aware of what they should legally be doing. If you explain what you need they may be willing to make the necessary changes.

If you are uncomfortable 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, if not, you can ask if you can bring a colleague of your choice with you. 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 your 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), Citizens Advice or the Equality Commission for Northern Ireland should be able to advise you. You can find contact details in the 'More information and support' section.

## What 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 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 or Law Centre, or from the Disability Law Service.





# ENDING WORK

## When should I stop working?

You may start thinking about giving up work completely earlier than you would have done if you had not been diagnosed with Parkinson's. This may be because working with Parkinson's is becoming too difficult or you would prefer to concentrate on other aspects of your life.

If you're 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 medication regime – and to take some time to adjust to this.
- Think about how stopping work will affect you emotionally and practically.
- 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.

- Speak to your employer or trade union to make sure you're leaving on the right terms, and at the best time. Some companies encourage their employees to attend training courses on preparing for retirement.
- Consider the alternatives such as working part time or volunteering.
- Call our helpline on **0808 800 0303** or speak to your local Citizens Advice or welfare benefits service for further information.

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

## Can I ask for redeployment?

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. This is known as redeployment. Remember that the job might be suitable if other reasonable adjustments are made, such as changing hours or location, or with the help of special equipment.

It is not enough for your employer to simply let you know about jobs within your organisation 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 end 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.

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

If your health deteriorates and you want to retire early, your pension may be able to offer you some financial support to help you cope. This is generally known as 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.

Because ill-health retirement is complicated and dependent on your own circumstances, it's usually best to talk to an independent financial adviser to make sure you are aware of all the options before making a decision. There's more information on the Pensions Advisory Service website. You can find their details in the 'More information and support' section.

# 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, as well as a break from caring, new social networks and friendships, better self-esteem and a better pension. However, combining your responsibilities has its own challenges.

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 own general health and wellbeing.

## Are carers protected against discrimination in the workplace?

If you care for someone with a long-term condition like Parkinson's you are protected from being discriminated against or harassed at work.

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

## 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 you need to take time off to look after the person you care for.

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.

“ I decided to go back to work a year after my husband was diagnosed. Work helps me stay strong and focus on something other than Parkinson’s, and ultimately we needed the money.

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 my husband’s condition. I wanted to be upfront from the beginning and not put any pressure on myself.

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. I use my caring experiences to provide support to the teams on carer’s needs.

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 for a walk. Look after yourself.”

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

Possible support options include:

- special leave arrangements to cover any time you need to care for your loved one (paid or unpaid which would be your employer's discretion)
- an employee assistance programme, if your workplace has one. This will be designed to deal with any personal or work-related problems you have that may affect your ability to do your job
- access to advice, support and information, perhaps 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 ask for flexible working hours?

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 how long you have been working at your company (the minimum for making a request is 26 weeks). Your employer must give serious consideration to your request but they can refuse if there are good business reasons for doing so. To find out more, visit [www.gov.uk/flexible-working](http://www.gov.uk/flexible-working)

Remember that there is nothing stopping you from talking to your employer informally. This may also be appropriate if you need a temporary change to your role.

### 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 invite a colleague to 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 allows employees to take a 'reasonable' amount of time off work to deal with an emergency involving a dependant. A dependant can include a:

- husband or wife
- partner
- child
- parent
- friend or family member who lives with you but doesn't pay rent
- person who reasonably 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. You might need to take leave because of:

- an emergency, such as a fall, that results in an ambulance visit
- unexpected problems with care arrangements
- the person you care for falling ill

- the need 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 decide you have to leave work, think about other options which may be available to you other than resigning, such as:

- a career break
- voluntary redundancy
- retirement

Employers are keen to keep skilled, experienced and committed staff, so they may be open to changing your role to fit around your caring duties. You may consider:

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

## What about my finances?

If you are thinking of 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. Call the employment and benefits adviser on our helpline on **0808 800 0303** to talk through your options.





# MORE INFORMATION AND SUPPORT

## Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson's nurses may not be available in every area, but your GP or specialist can tell you about local services.

You can find out more at [parkinsons.org.uk/nurses](https://parkinsons.org.uk/nurses)

## Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

Our helpline can also put you in touch with one of our local advisers, 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](https://parkinsons.org.uk/localtoyou)

You can find details of our local groups and your nearest meeting at [parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)

You can also visit [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum) to chat to other people with similar experiences on our online discussion forum.

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.

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

**[www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)**

## **Advisory, Conciliation and Arbitration Service (ACAS)**

This organisation provides impartial advice for both employers and employees who are involved in an employment dispute or are seeking information on employment rights and rules.

**0300 123 1100**

Text Relay:

**18001 0300 123 1100**

**[www.acas.org.uk](http://www.acas.org.uk)**

## **Citizens Advice**

### **Citizens Advice England**

**03444 111 444**

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### **Citizens Advice Wales**

**03444 77 20 20**

### **Citizens Advice Northern Ireland**

**028 9023 1120**

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

## **Citizens Advice Scotland**

**[www.cas.org.uk](http://www.cas.org.uk)**

## **Disability Law Service**

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

**020 7791 9800**

**[advice@dls.org.uk](mailto:advice@dls.org.uk)**

**[www.dls.org.uk](http://www.dls.org.uk)**

## **Disability Action (Northern Ireland)**

This organisation has a number of programmes that help people with disabilities find employment and support them in their place of work.

**028 9029 7880**

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

## **Do-it**

This is an online database where you can search volunteering opportunities in your area.

**[www.do-it.org.uk](http://www.do-it.org.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 includes advice on the Equality Act and how it applies to 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**

**0808 800 0082**

**[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)**

## **Information and guidance on the Equality Act**

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)**

## **Law Centres**

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

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

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

To find your nearest Law Centre in Scotland visit

**[www.govanlc.com/salc](http://www.govanlc.com/salc)**

## **Pensions Advisory Service**

Provide detailed information on ill-health retirement.

**[www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)**

## **Volunteering Matters**

This organisation helps people of all ages work with their local communities, and lists local volunteering opportunities.

**020 3780 5870**

**[www.volunteeringmatters.org.uk](http://www.volunteeringmatters.org.uk)**

## **For employers**

### **Business Disability Forum**

Business Disability Forum is a not-for-profit member organisation that makes it easier and more rewarding to do business with and employ disabled people.

**020 7403 3020**

Textphone: **020 7403 0040**

**advice@businessdisabilityforum.  
org.uk**

**www.businessdisabilityforum.  
org.uk**

## **For carers**

### **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.

**employers@carersuk.org**

**www.employersforcarers.org**

### **Carers UK Adviceline**

Provides advice and information on carers employment rights.

**0808 808 7777**

Email contact form at

**www.carersuk.org**

## Work and Parkinson's (INFOB0024/2018)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thank you!

### 1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
  - I care for someone with Parkinson's
  - I have a friend or family member with Parkinson's
  - I'm a professional working with people with Parkinson's
  - Other (please specify)
- 
- 

### 2. Where did you get this information from?

- GP
  - Specialist
  - Parkinson's nurse
  - Parkinson's UK local group
  - Parkinson's UK local adviser
  - Ordered directly from us
  - Call to the helpline
  - Other (please specify)
- 
- 

### 3. Has it answered all your questions?

- Yes, completely
- Not sure
- Yes, mostly
- Not at all
- Partly

### 4. How easy was it to understand?

- Very easy
- Quite difficult
- Easy
- Very difficult
- Not sure



## 5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- |   |   |
|---|---|
| <input type="checkbox"/> It helped a lot    | <input type="checkbox"/> It didn't help       |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change          |   |

## 6. What is your ethnic background?\*

- |   |  |
|---|--|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed         |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese                | <input type="checkbox"/> White other   |
| <input type="checkbox"/> Other (please specify) |  |
- 

\*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

## Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

## If you've answered yes to any of these options, please complete your details below.

Name

---

Address

---

Email

---

Telephone

---

## How would you prefer us to contact you?

- Email    Post    Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](https://parkinsons.org.uk/termsandconditions)



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

**Bela Gor, solicitor and  
Legal Director at Business  
Disability Forum**

**Joanna Lawson, Associate  
at Mishcon de Reya LLP**

**Victoria Griffith, Benefits  
and Employment Adviser,  
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 either people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's or Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

### **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.

### **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**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and 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.

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**

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](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**  
**[parkinsons.org.uk](http://parkinsons.org.uk)**

Order code: INFOB0024

Last updated February 2018. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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