

Introduction

Living with Pompe means that you have additional rights at work. These stem from legally protected characteristics listed in the **Equality Act** and include a right to reasonable adjustments so you're not at a disadvantage.

You can visit www.acas.org.uk/reasonable-adjustments and talk to your HR manager to find out about agreeing any changes your employer can reasonably make. These could include whether you can take time off work for appointments, work more flexible hours, or have changes made to your job or place of work. If you're not sure what adjustments you need, **Access to Work** grants can pay for specialist assessments.



Your rights at work

Here's a summary of your legal rights at work and support available to help you keep working.

- Your employer is not allowed to discriminate against you because you are disabled.
- They must keep your job open for you and can't pressure you to resign because you've become disabled.
- Your employer must make reasonable adjustments to your place of work, the job you do, or the terms and conditions of your employment.

So, what are reasonable adjustments at work? These could include the following:

- Adapting the workplace, for example by providing ramps.
- Flexible working hours, time off for appointments or more breaks.
- Giving you alternative duties or moving you to a more suitable workplace.
- Providing specially adapted equipment, such as a computer, keyboard, telephone, chair, or desk.
- Counting and recording disability related absence separately to sick leave.
- Providing a support worker.



Your employer will only be required to make adjustments that it would be 'reasonable' for them to implement. This includes consideration of the cost involved, the impact on others / their business, and whether the adjustments have a real prospect of being effective. Your employer is responsible for paying for the cost of any adjustments, though the Government's **Access to Work scheme** may be able to contribute towards the cost. More information can be found at: www.gov.uk/access-to-work.

TOP TIP: Start the conversation!

Medical retirement

"When I got my diagnosis, I told my manager and together we looked at ways to make my working day easier. I received a new computer and agreed to days when I can work from home and with hours that suit me. This has really taken away a lot of stress"

Person living with Pompe

Reasonable adjustments are there to support you in the workplace, however if you feel that medical retirement is the next step for you then you need to do the following things:

- Get medical proof confirming your condition.
- Get confirmation from your employer that ill health is the only reason for your retirement.
- Complete a copy of the ill health retirement application form from your pension scheme.

Some benefit schemes which include final salary and career average pensions can begin paying your pension early in the event of permanent ill health. Usually, this type of pension is reduced if it's paid early. But many schemes won't make this reduction if you take your pension early due to ill health.

"I had worked for many years and knew it was time to retire. It was a scary decision but thankfully I received all the information I needed from AGSD UK.

I could talk honestly and not feel judged or pressurised to stay in work. I'm now retired. My employer was great and helped with every step."

Person living with Pompe

It's not possible to claim state pension before your state pension age, but you might be entitled to other state benefits such as statutory sick pay.

TOP TIP: Do your research around pensions and see if leaving work is financially viable!

You can find out more and get support with benefits and employment rights by contacting AGSD-UK's friendly care and benefits advisors.

Just email info@agsd.org.uk and we'll be in touch!