

How to apply

So, having summarised some of the types of benefits available, you also need support on how best to tackle the endless forms that go with the process of applying for them. Here are a few generalised points that may be helpful:

- Read the questions fully before attempting to answer
- Do a trial run with a copy of the form – it will help you to make sure all your responses are appropriate and in the right places
- The way you are affected by your porphyria most likely varies day to day, but when completing forms think about your abilities on your worst days
- Use your own words and try to remember personal experiences to illustrate your difficulties
- If you have problems with writing clearly, get someone else to write the answers, and sign to confirm you agree
- Keep a copy of the completed form (photo, photocopy or scan)
- It is vital to support your claim/application with medical evidence from your doctor or specialist
- Ask for additional help, e.g. from the Citizen's Advice Bureau or medical professionals - some GP surgeries also have access to someone who may help with form filling for benefits
- If you are unsuccessful initially, appeal or ask for your case to be looked at again

Disability Rights UK www.disabilityrightsuk.org/ and their publication, the Disability Rights Handbook are extremely useful for further information and help with forms. The BPA have a copy available for patients to use at meetings.

Travel and life insurance

Getting insurance can be tricky for people with a pre-existing medical condition. Some BPA members have had success with Tesco, American Express, Insure and Go and Freedom Insurance, but it all depends on individual circumstances.

On some price comparison websites you can compare companies that cover medical conditions as part of their travel policies: www.moneysupermarket.com/travel-insurance/pre-existing-medical-conditions/ and www.comparethemarket.com/travel-insurance/with-medical-conditions/.

These particular websites recognise porphyria and also AIP, CEP, EPP and HCP individually. Life insurance may be more difficult; you may need to appeal an initial refusal. If so, you will need to gather all the information relevant to your individual case. A letter from your doctor will help.

NOTE: This leaflet may not cover all situations and is not a statement of the law. To the BPA's knowledge, the information was accurate at the time of printing.

Useful contact details

BPA telephone helpline: 0300 30 200 30

BPA email helpline: helpline@porphyria.org.uk

European Porphyria Network: www.porphyria-europe.com

Citizen's Advice Bureau: www.citizensadvice.org

Disability Rights UK: www.disabilityrightsuk.org

Disability Law Service: www.dls.org.uk

GOV.UK: www.gov.uk

Scope: www.scope.org.uk

British Porphyria Association

Charity No: 1089609



Claiming benefits and concessions:

Acute porphyrias

Patient information leaflet



Check your entitlements

If symptoms of porphyria are affecting your ability to work, you may be trying to tackle the benefits system for the first time. Benefits available will depend on your personal circumstances. So, this guide aims to provide a summary of the types of assistance available, and direct you to places/resources that will be able to help you more.

Not all benefits are means tested, some – e.g. Personal Independence Payment (previously Disability Living Allowance for adults) – are there to help you manage the extra costs associated with being disabled or having a long-term health condition. These are not affected by your income and savings. Other benefits are means-tested and are designed to replace or top-up earnings – e.g. ESA or Tax Credits – or help with essential costs, e.g. Housing Benefit.

Try one of the following benefits checkers to see what you may be entitled to:

www.turn2us.org.uk/benefits_search.aspx or www.entitledto.co.uk/.

Statutory Sick Pay (SSP): If you are unwell and can't work, you may be able to get SSP. This is the minimum you're entitled to, but some employers may have more generous schemes.

Employment and Support Allowance (ESA): If you haven't been able to work for more than 28 weeks because of illness/disability, you may be able to get ESA. Go to www.gov.uk/employment-support-allowance to find out.

Personal Independence Payment (PIP)/Disability Living Allowance (DLA): If you have a long-term health condition or disability and have problems with daily living activities or mobility, you may be able to claim PIP. To qualify you must:

- Be aged between 16 and 64
- Have had these difficulties for three months and expect them to last for at least another nine months

New claims for DLA only apply to children under 16.

Disability Law Service provides some useful pointers for filling out DLA forms in their factsheet: www.dls.org.uk/.

Housing Benefit/Local Housing Allowance: If you're renting a property and on a low income, you could get help to pay your rent. You can get this even if you're working. It's paid by your local council. Find out more at www.gov.uk/housing-benefit.

Support for Mortgage Interest: If you're claiming a benefit such as ESA or Income Support, you might be able to get help towards interest payments on your mortgage or to help pay the interest on loans you've taken out to repair/adapt your property to make it more suitable for your needs. Find out more at www.gov.uk/support-for-mortgage-interest.

Help with Council Tax: Each local council has their own Council Tax Reduction scheme so the help you get depends on where you live; contact your local council for further details.

Tax credits: You should be able to claim tax credits if you have a disability and you usually work 16 hours or more a week, and earn less than £18,000 per year (approximately). Check whether you qualify at www.gov.uk/qualify-tax-credits-quick-questionnaire.

For support and more on legal rights to help you keep your job when you are ill or disabled, see www.moneyadviceservice.org.uk.

Other benefits/concessions include:

Blue Badge Scheme: Concessions apply to on-street parking and can include free use of parking meters

and pay-and-display bays. Badge holders may also be exempt from limits on parking times and can park for up to three hours on single and double yellow lines as long as they are not causing an obstruction (except where there is a ban on loading or unloading, or other restrictions).

Could I qualify? If you receive the higher rate mobility component of DLA you will automatically qualify, but there are other eligibility criteria too. Please see www.gov.uk/apply-blue-badge for further information.

Motability Scheme: this scheme enables disabled people to lease a new car, scooter or powered wheelchair, using their mobility allowance. If you receive the higher rate mobility component of DLA or the enhanced rate mobility component of PIP you may be eligible to join the scheme. See www.motability.co.uk/ for more information.

Disabled Person's Railcard: allows you to get a third off most rail fares in Britain. If you're travelling with an adult companion, they can also get a third off. A number of conditions apply, but if you receive PIP or DLA (mobility element or middle/higher personal care element), or have a Motability car, you will most likely be eligible. Apply at www.disabledpersons-railcard.co.uk/.

Adaptations for your home: A health and social care assessment with social services or a referral to an occupational therapist (OT) can be a good first step towards getting the support you need. A **Disabled Facilities Grant** can help with certain costs incurred in adapting your home to ensure you can remain living there. Your local council will need to assess your individual needs. Please see www.gov.uk/disabled-facilities-grants/overview and www.disabilityrightsuk.org/housing-grants for more information.