

How to apply

So, having summarised some of the types of resources 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.

Lifestyle support

Owl Patrol: this night camp is the Flagship event of the XP (Xeroderma Pigmentosum) Support Group and is an annual weekend camp for XP families. XP is also a light sensitive condition. It provides indoor activities during the day and outdoor activities at night. Although run by the XP support group, they welcome other families with light sensitive conditions to the camp, such as those with EPP. Please see <http://xpsupportgroup.org.uk> for more information.

This leaflet may not cover all situations, also laws and benefit schemes can change over time, so it is important to carefully check what might be available.

Useful contact details

BPA telephone helpline: 0300 30 200 30

BPA email helpline: helpline@porphyria.org.uk

European Porphyria Network: <https://porphyria.eu>

British Association of Dermatologists:
www.bad.org.uk

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

Other potential grants providers

- Family Fund: www.familyfund.org.uk
- Family Action: www.family-action.org.uk
- Your local Lions Club

British Porphyria Association

Charity No: 1089609



Claiming benefits and concessions:

EPP

Patient information leaflet



Financial and social support

Symptoms of EPP may affect all aspects of daily life, but there are many things that can be done to improve the situation. Help available will depend on your personal circumstances and often where you live. So, this guide aims to provide a summary of the types of support available, and direct you to places/resources that will be able to help you find out more.

Much of the information given here relates to help that is available for children with EPP, however that is not to say that you can't try as an adult too.

The following people may be helpful in finding out what is available in your area:

- GP or specialist
- Family key worker
- Special educational needs coordinator
- Occupational therapist

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 (for example, some patients have been successful with getting their local council to fund light proofing to their home).

Some benefits/concessions may also be available to you depending on your individual circumstances.

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 difficulties for three months and expect them to last for at least nine months

New claims for DLA only apply to children under 16.

Despite the fact that the boxes on the form do not specifically reflect the problems those with EPP have, there has been some success with EPP patients getting the lowest rate of personal care, which can help with paying for some of the extra costs associated with having EPP, such as gloves and protective clothing.

Disability Law Service provides some really useful pointers in their factsheets:
www.dls.org.uk

Blue Badge Scheme: Concessions apply to on-street parking and 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). Please see www.gov.uk/apply-blue-badge for information.

Could I qualify? People with EPP are unlikely to fit the usual criteria, but people with hidden disabilities can now apply for a Blue Badge. Having a light-proofed car can be central to the application. The car is the 'safe haven' and parking close to buildings is essential to minimising pain and suffering. You may need help and support from your GP or specialist when applying.

Light proofing/window films for your home or car: Your GP can provide a referral to an occupational therapist (OT), or social services may do a health and social care assessment to assess your individual needs. You may need to be persistent to achieve one of these assessments. However, it is worth doing, as your local council may then be prepared to pay for window films for your home.

A **Disabled Facilities Grant** may help with certain costs incurred in adapting your home to ensure you can

remain living there, such as window films and lighting alterations. Please see the following www.gov.uk/disabled-facilities-grants/overview and/or www.disabilityrightsuk.org/housing-grants for more information on Disabled Facilities Grants.

Window film grants can sometimes be provided for cars by charities. The BPA provides a grant service (please contact us on 0300 30 200 30 or helpline@porphyria.org.uk for more details) and local charities are also worth contacting as they like to help families in the local community. Various other charities that may be able to help in some way are listed overleaf.

Special Educational Needs (SEN): can affect a child's ability to learn, and could include physical needs such as the needs/precautions that must be taken to protect a child with EPP. Contact the SEN coordinator (SENCO) in your child's school or nursery for more information.

SEN support can help with making reasonable adjustments to classroom facilities to ensure a child can access resources with minimal pain and suffering. If your child has an SEN statement or Education, Health and Care Plan (EHC) that includes transport requirements, your council is obliged to provide them. The Children's and Families' Act in 2014 changed many rules, so be sure to get up-to-date advice.

Find more information about SEND at:
www.gov.uk/education/special-educational-needs-and-disability-send-and-high-needs

SOS!SEN also offers free, independent and confidential advice and support on SEN matters in England and Wales during term time: 020 8538 3731 or www.sossen.org.uk

remain