

patient & family support services

The Gauchers Association employs a Patient and Family Support Worker to help with any non-clinical advice and information, offering an individual advocacy service.

Support comes in many forms and it is based around the needs of each individual. Our service can support you with a whole range of issues such as benefits applications; from the start of the process through to appeals e.g. Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Employment Support Allowance (ESA). It could be attending clinical appointments, accessing home adaptations, liaising with homecare teams, getting support at school, college or university and more.

Different types of areas we can provide information & support

What is DLA (Disability Living Allowance)?

DLA is the benefit for children under 16 who have difficulties walking or need more looking after than a child of the same age who does not have a disability. You can order the application form by phoning 0345 712 3456. For more information see

<https://www.gov.uk/disability-living-allowance-children>

What is PIP (Personal Independence Payment)?

PIP is replacing DLA (Disability Living Allowance) for 16-64 year olds living in the UK. If you currently receive DLA and are aged 16-64 you will be invited at some point to claim for PIP. The payment is to help with some of the extra costs caused by long term ill health, a disability that affects your mobility or your ability to do activities of daily living (such as washing, dressing, cooking etc.). You can claim this benefit regardless of your employment situation.

If you think you may be entitled to PIP, phone the DWP (Department for Work and Pensions) free on 0800 9172222 and they will send you a 'How your condition affects you' form. Once this is returned you will normally get invited for an assessment with an independent healthcare professional. A decision is then made on your PIP claim.

For more information visit www.gov.uk/PIP/overview



What is ESA (Employment and Support Allowance)?

If you are ill or disabled ESA will give you financial support if you are unable to work and personalised help so you can work if you are able to. It is dependent on your income or previous payment of National Insurance contributions.

The quickest way to claim is by phoning the DWP (Department for Work and Pensions) free on 0800 0556688. You will then be invited to a work capability assessment to decide whether you qualify.

For more information see:

www.gov.uk/employment-support-allowance/overview

Benefits and Appeals

If it comes back that you are not eligible for the benefit you have applied for all is not lost. Our Patient and Family Support worker can support you through any stage of the process, from completing the initial form, through the mandatory reconsideration process and to an appeal.

Education

Our Patient and Family Support Worker can support with attending meetings, giving information to the school about Gaucher Disease, help with appeals, support to fill out Disabled Students' Allowance (DSA) forms for university students and more.

Travel Insurance

Are you planning on travelling abroad? Hopefully your travels will go without a hitch. But what would happen if you fell ill or got injured in a foreign country? You may need to pay to get treated or flown home. Travel insurance gives you peace of mind. You must disclose all your health conditions including Gaucher disease. The Gauchers Association has a list of providers that our members have recommended who will insure people with Gaucher disease.

This service is available (Monday to Thursday) and you can call on **01453 54923**

Alternatively, call or text the Patient & Family Support Worker's mobile on **07795 192311**

If you would prefer to meet in person, we can arrange to meet you at home or at a local coffee shop.

Contact us if you would like a copy.

