

BDFA Small Grants Scheme

The BDFA appreciates that families are often faced with financial challenges when caring for someone with Batten disease. Whilst there may be various options available, the BDFA aims to provide assistance to help families cope with these circumstances and has introduced a Small Grants to Individuals Scheme. This is designed with a streamlined application process, to be able to provide a rapid practical response to difficult situations.

The grants can be used for a number of different things, for example:

A larger capacity washing machine. This may be necessary if there is a need to be frequently washing large amounts of bedding for someone who is incontinent. The grants can also help with utility bills such as heating or telephone. This can give families peace of mind to enable them to maintain a constant temperature for the person they care for or to keep in contact with health professionals when you are caring for someone at home.

If your child or young person is in hospital some distance from home we also can help with the cost of travel and subsistence to provide support at this stressful time.

Children or young people with Batten disease often have access to a stimulating sensory environment and equipment when they attend school, respite care or day care but very few have these facilities at home. Our funding can help provide these at home.

To be eligible, the person being cared for must have a form of Batten disease and the BDFA can offer a grant of up to

£500 which can be used in many different ways. Please contact the BDFA Support and Advocacy Partner on **0800 046 9832** for more information.

Where can I get additional information and support?

The BDFA offers support to any family member, friend, professional or organisation involved with caring for a child with any NCL disease throughout the UK. We provide informed guidance and assistance as well as seeking to increase awareness of the disease and facilitate future research to identify potential therapies and ultimately a cure.

We organise conferences and workshops, and are able to arrange connections with other affected families. The BDFA also coordinates a Small Grants Scheme that can provide assistance for a range of needs.

The BDFA has a Support and Advocacy Partner who is able to assist with many of the issues highlighted in this document and can discuss each in greater detail and on a more personal basis.

They can be contacted via our Freephone Helpline: **0800 046 9832** or email: support@bdfa-uk.org.uk.

There are a number of local and national organisations who are also able to offer various forms of support and information that will be relevant to families. Please contact the BDFA for further information.

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Freephone Helpline: **0800 046 9832**

Email: support@bdfa-uk.org.uk

Website: www.bdfa-uk.org.uk

Financial Support – Benefits and Tax Credits

This leaflet was designed to answer some of your questions about financial support available when you are caring for a child or young person living with a diagnosis of an NCL disease. The BDFA Support and Advocacy Partner is available to answer any questions you might have concerning the information in this leaflet. They can be contacted on **0800 046 9832** or by email on: support@bdfa-uk.org.uk

As there are so many different benefits and tax credits to apply for it can sometimes be difficult to work out which are applicable to you. Having a child or young person with a diagnosis of an NCL disease could mean that a family member has had to give up work in order to care for their child, leaving the family under increasing financial strain. There are, however, a wide range of benefits which can support families with their living costs, heating bills and even items such as cheaper cinema tickets.

Where should I start?

The best place to start is with your Local Authority. Your social worker, if you have one, should be able to make an assessment of your child's needs and decide if the Local Authority will be able to offer any funding. You cannot be refused an assessment. Each Local Authority will have their phone number online or in a telephone directory. You will need to request a social work assessment to explain to them about your child or young person's disability. If you are the carer of a child or young person you will also be asked about what this caring entails. This will mean a social worker coming to visit you in your home and asking you some questions about your child or young person and their needs.



Once the assessment is complete, the Local Authority will decide if your child or young person will receive any provision. If you are eligible for services provided by the Local Authority, a care plan will be made which will state which services will be provided to meet your child's needs.

If you are unsuccessful in obtaining services your social worker should write to you clearly explaining why services are not being put in place.

Can I receive support if I am caring for my child or young person?

If you are the child's main carer you are entitled to an assessment from the Local Authority too. This can either be done with your child's assessment or it can be completed separately. The results will be used to ensure that your child or young person is receiving the correct services. The social worker will be looking at whether you may need extra support in the home and will assess whether you would be able to use respite services.

What happens after the assessment?

When the Local Authority has finished its assessment you will be notified about what services you and your child or young person have been assessed as needing. You will then be eligible for Direct Payments. This means you can either accept the services which the Local Authority will give you or you can be paid cash and you can find your own provider of the services. Direct Payments can be used to employ Personal Assistants or to find respite providers.

Some families prefer this as it gives them a greater choice and more independence. You must however be able to manage the Direct Payments yourself. You are not obliged to take them if this is something you feel you don't want to do and you still have the option of taking the Local Authority Provision. You cannot use Direct Payments to pay a relative or someone who lives in your household.

The Local Authority must pay you at a rate equivalent to their estimated cost of the services needed and to meet the needs of paying a carer's insurance, holiday and sick pay. If you decide to choose a more expensive way to provide care for your child, you will be liable to pay the deficit. Your child's needs should be assessed on a yearly basis but do let your social worker know if their condition changes before your review.

Will I have to contribute towards the services we receive?

The Local Authority may ask for a contribution for services which they provide. They will let you know if you are expected to pay charges and these will be means tested.

However, you can't be charged if you are receiving Income Support, Working Tax Credit or Disabled Person's Tax Credit.

Personal Independence Payments (PIP)

These payments were introduced in April 2013 to replace Disability Living Allowance for people aged 16-64 and are tax free. It is for people who need support in their everyday life. To apply, you will need to ring the Department of Work and Pensions and request an application pack. Someone else can ring for a young person or adult as long as they are with them.

There are two parts of PIP which can be paid to you. Both can be paid at a standard or enhanced rate. You will need to fill in the application form which has been sent to you in as much detail as possible. If you would like support whilst you are going through this process or if you have any questions please contact the BDFA by ringing the Support Helpline.

In the 'additional information' box you need to state how the disease affects the young adult/adult. You also need to put all relevant information on the form in order to help the application process move forward. You will need to comment on how well your young adult/adult can do the tasks listed below:

Ten daily living activities:

- Preparing food
- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

Two mobility activities:

- Planning and following journeys
- Moving around



You will be asked to give a score between 0-12 for each task on the form. It may be helpful to make a diary as this can be provided as evidence when you send off the form. The points are then added together to see which rate of PIP your young adult/adult will receive. You need 8 points for the standard level of provision in the daily living tasks and 12 points for the enhanced provision. This is the same for the mobility section.

You may then be asked to have an assessment with a health professional. This can be done in your own home. The provision is reviewed regularly to ensure that everyone is still receiving the right provision.

Currently not all postcodes are using PIP. From October 2015 all those over 16 still receiving DLA will be contacted and asked to complete a PIP assessment. Everyone aged 16-64 will be asked to apply for PIP by May 2018. This will happen even if you have been awarded DLA on a long term basis. You will need to apply within 4 weeks of being contacted and while the assessment process is taking place you will still receive other benefits such as the Motability Scheme and Blue Badges.

If you are successful, the carer of the young person will still be able to claim Carer's Allowance and you will be able to continue on the Motability and Blue Badge schemes. If your child or young person is in receipt of PIP you will be exempt from the benefits cap which came into place in April 2013.

If you do not agree with the amount your young adult/adult has been awarded you may ask the Department for Work and Pensions (Social Security Agency, Northern Ireland) to reconsider the decision. This is called a 'mandatory reconsideration'.

You need to do this within a month of receiving the decision. If you still do not agree with the decision after the mandatory reconsideration you should apply to the HM Courts and Tribunals Service (Appeals Service, Northern Ireland) and attach a copy of the mandatory reconsideration for review.

If you would like to speak to them about any aspect of arranging your child's funeral please call them or visit their website: <http://www.childfuneralcharity.org.uk/>
Tel: **01480 276088**.

The BDFA will be here to support you at any point throughout your bereavement. Please ring the Support Helpline for further support: **0800 046 9832**.

Motability Scheme

If your child or young person is over 3 years old and is receiving the higher rate of mobility DLA payment or the enhanced mobility PIP payment then you are entitled to apply to the Motability Scheme. This will enable you to lease an adapted car. To apply for this please ring the Government helpline:

Motability

Telephone: **0845 456 4566**

Textphone: **0845 675 0009**

Monday to Friday, 8.30am to 5.30pm

You can also look at the Motability website to see which cars are available: <http://www.motability.co.uk/>



The Blue Badge scheme and road tax

If your child gets the highest rate of DLA mobility component, you can apply for road tax exemption and for a Blue Badge for disabled parking. The Blue Badge may also be awarded where a child is aged two or over and has a permanent disability which makes walking difficult, or where they are aged under two and either need to be accompanied by bulky medical equipment or kept near a vehicle so that they can receive medical treatment at short notice.

If you get the enhanced mobility component of PIP you will also be eligible for an exemption from road tax. If your child qualifies for the standard mobility component you may be

eligible for partial help with the road tax.

Eligibility for the Blue Badge will depend on the number of points awarded for certain activities which relate to mobility. Qualifying points will also depend on which part of the UK you live in. Contact the BDFA Support Helpline for further information.

Benefits if your child goes into hospital

If your child or young person has to stay in hospital for an extended period your benefits could change.

Carer's Allowance: If you go into hospital for more than 12 weeks your payments will cease. If the person you are looking after goes into hospital your allowance will stop when their DLA or PIP payments stop.

Child Benefit: This will stop after 12 weeks unless you can show you are regularly spending money on the child or young person in hospital.

Disability Living Allowance (DLA): This will stop after 12 weeks and your Motability Scheme may cease.

Income Support: If you go into hospital you should still be paid your Income Support, however, if you receive the Carer Premium this will stop 8 weeks after your Carer's Allowance ceases.

Personal Independent Payments (PIP): These will stop after 4 weeks of being in hospital.

CEA Card

This card will ensure that the carer of a disabled person gets a free ticket when they accompany them to the cinema. You can apply for the card on the website and find your nearest local cinema which will accept the card. Please visit: www.ceacard.co.uk

Local Offers

Each Local Authority has a duty to provide a Local Offer. This is for children and young people from 0-25 who have a disability and should give a list of all the services which are available to them in the local area. The provision should span health, education and social care.

The Local Authority must also provide you with information about special education provision, short breaks services, information on leisure activities and information on childcare for disabled children. If you are not aware of any of these services in your area please contact your Local Authority as it is their duty to let you know about this information.

Council Tax Reduction

If you are the main carer for your child or young person you may be entitled to a 25% reduction in Council Tax. You may be eligible for further reductions if you have a room which is used to store equipment, if you have a second bathroom which is used for your child, if you use a bedroom as a sensory room or if you have enough space to have wheelchair doors in your home.

You may be able to go to a lower pay Band if this applies to your household. In Scotland your water bill may be able to be reduced if the above conditions apply to your home. Please ring your local Council Tax office to speak to them about individual situations.

VAT Exemptions

You should receive VAT exemptions for products such as wheelchairs, adapted beds, hoists, ramps, stair lifts, Braille paper, cars with adaptations and some medical appliances. Before you purchase such items you may need to write to your supplier to tell them about your child's condition. There may be times when you have to pay VAT but it is always worth contacting the company first to check what you are entitled to.

Cold Weather Payments

If you receive Income Support, Jobseeker's Allowance, Employment and Support Allowance or Universal Credit and you have a disabled child or young person you may be eligible for cold weather payments.

You are entitled to £25 for every 7 days of cold weather from 1st November and 31st March. If you are eligible to receive this you will be paid automatically 2 weeks after each 7 days of cold weather.



Watersure Scheme

This scheme is designed to help families who have a low income or use more than the average amount of water. To apply for this you will need to be receiving other benefits such as Income Support or Universal Credit.

If you feel that due to your child's diagnosis of Batten disease you use more water than average then you will need to ring your local water supplier and they may ask you to send a doctor's certificate. You can only use this scheme if you live in England or Wales.

Funeral Payments

Funerals can be expensive and we understand that this is an important process for families after they lose a child. You may be eligible for help with funeral costs. If you are from a low income family or receive one of the following benefits then you can apply:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance
- Pension Credit
- Housing Benefit
- The disability or severe disability element of Working Tax Credit
- One of the extra elements of Child Tax Credit
- Universal Credit

They may ask some difficult financial questions when you apply, such as how much other money is available to pay for the funeral. This is asked because not everyone will receive the same amount. You will need to apply 3 months after the death of a family member. To find out more call the Government Helpline:

Bereavement Service Helpline

Telephone: **0345 606 0265**
Welsh language: **0345 606 0275**
Textphone: **0345 606 0285**
Welsh language: **0345 606 0295**
Monday to Friday, 8.00am to 6.00pm

The Child Funeral Charity assists families in England and Wales who have to arrange a funeral for a baby or a child under the age of 16. Please speak to the BDFA Support and Advocacy Partner if you would like to be referred to the Child Funeral Charity.

Disability Living Allowance (DLA)

Any child or young person who is under 16 living with a disability is eligible to receive DLA. This can be claimed even if both parents are still working. Again there are different rates depending on the needs of the child.

The Care Component rates are:
Lower Rate: If your child or young person needs help with personal care for about an hour a day.

Middle/Higher Rate Day: If your child or young person needs frequent help with personal care throughout the day and someone to check on them throughout the day.

Middle/Higher Rate Night: If your child or young person needs help with personal care at least twice a night as well as someone to check on them twice a night.

The Mobility Rates are:
Lower Rate: Paid to you if you are able to walk but need assistance most of the time.

Higher Rate: Your child or young person will need to be in one of the following categories:

- unable to walk
- virtually unable to walk
- cannot walk without the effort required endangering their life or seriously affecting their health
- both legs amputated at or above the ankle, or they were born without legs or feet; regardless of whether they wear artificial limbs
- both deaf and blind (80% deaf and 100% blind)
- assessed as 'severely visually impaired'

Many children and young people living with Batten's disease may begin with being awarded the lowest rate of DLA but as the disease progresses the level of DLA support will need to be reviewed as the highest level of DLA should be awarded as the disease progresses. This is something you may wish to let the assessment team know about.

You can claim DLA if you care for the child or young person as if you are their parent. This includes foster parents, step parents, grandparents and brothers or sisters. Only one application per child or young person can be made. To order an application form ring the DLA Helpline:

Disability Living Allowance Helpline

Telephone: **0345 712 3456**
Textphone: **0345 722 4433**
Monday to Friday, 8.00am to 6.00pm
Website: **www.gov.uk/disability-living-allowance-children/how-to-claim**

Northern Ireland:
Website: **www.gov.uk/disability-living-allowance-children/how-to-claim**
Telephone: **0289 090 6178**

Cerebra have created a guide to the DLA form. This guide explains what each question means and gives you helpful tips on how to answer the questions. It also gives you advice on how to appeal if you are unhappy with the decision. You can request a printed copy of the guide by calling: **0800 328 1159** or emailing: **info@cerebra.org.uk**

You can also find an electronic copy on the Cerebra website: **<http://www.cerebra.org.uk/English/Pages/home.aspx>**

The forms can be long and complex. If you need help filling these out please contact your nearest Citizens Advice Bureau or the BDFA. It is important to put as much information about your child on the form as you can. Claims usually take 40 working days.



If you disagree with the amount your child or young person has been awarded you can ask the Department of Work and Pensions to reconsider their decision. This is called a mandatory reconsideration.

If you still do not agree with them after this process then you will need to appeal to the HM Courts and Tribunals Service and attach a copy of the mandatory reconsideration for review.

Carer's Allowance

If you, or a relative living in your home, spend over 35 hours a week caring for your child then you could be eligible for Carer's Allowance. The amount of savings you have is not taken into account. To be eligible for this you must be over 16 and caring for a child in receipt of DLA. You cannot be in full time education or earning over £102 a week and you also need to reside in the UK.

The current rate for Carer's Allowance is £61.35 per week. This will be paid to you until 8 weeks after the person you are caring for has passed away. If you are in receipt of any other means tested benefits you should receive a carer premium.

You can claim online at:
www.dwp.gov.uk/carersallowance/ or pick up a form at your nearest Job Centre.

Income Support

Income support is usually for people who are not expected to look for work e.g. usually those who are caring for a family member. This can be paid alongside Carer's Allowance and provides money for daily living expenses. The amount of support depends on individual circumstances.

You are also entitled to more income support in the form of 'premiums' if you are a carer and if you have a disabled child. You will be unable to claim if you or your partner's capital or savings is above £16,000.

You can ask for an application form at your local Job Centre or download the application form from:
www.gov.uk/income-support.

Child Benefit

You should receive Child Benefit if you have a child or young person who is 16 or under or under 20 if they stay in approved education. For your eldest or only child or young person you will receive £20.50 per week and for every other child or young person you will receive £13.55.

If your child or young person goes into residential care or into hospital for 12 weeks you will need to let the Benefit office know as you usually won't be able to receive Child Benefit after this time unless you can show you are still regularly spending money on your child.



You can download an application form from:
www.gov.uk/child-benefit/how-to-claim

Child Tax Credit

You will be eligible for Child Tax Credit if you have a child or young person under 16 and are on a low income. Your income will be taken into account, if you have any. Currently children and young people who are on the highest level of DLA can receive £1255 of Child Tax Credit. This will not affect your Child Benefit.

To request an application form, call the Tax Credits Helpline:
0345 300 3900.

Carer's Credit

If you spend 20 hours or more a week caring for your child, then you should be entitled to Carer's Credit. It will help to build up your National Insurance contributions and you will then start to build up your entitlement to state pensions. To be eligible the person you are caring for must be receiving DLA or PIP. To claim download a form from:
www.gov.uk/carers-credit/how-to-claim

Universal Credit

This is a new benefit like PIP that will not come into effect across all of the UK until February 2015. It will replace means tested benefits such as:

- Child Tax Credit
- Housing Benefit
- Income based Jobseeker's Allowance
- Income based Employment and Support Allowance
- Income Support
- parts of the Social Fund
- Working Tax Credits

Many of these benefits will be around for a while yet but with Universal Credit you may be eligible for free dental work, prescriptions and free school meals. You may also be able to use it for hospital fares. If you live with a partner you will not be eligible if you have savings above £16,000 and your income will also be taken into account.

Universal Credit is usually only given to those who are actively looking for work but if you are caring for a disabled child or young person you are still eligible to claim. The amount paid to you will depend on your circumstances. If you are receiving DLA or PIP this will not be taken into account. If

you receive the highest level of DLA or PIP you will be entitled to £362.92 and £229.17 for other children and young people in your household within your maximum amount.

If you care for your child or young person, £148.61 will be added to the amount. If you pay for registered childcare so you can stay in work, you will receive £532.29 or £912.50 for two or more children.

Universal Credit may also pay for certain charges related to mortgage or rental costs but if you are not eligible for this you may get Work Allowance at £222 on the lower rate or £536 on the higher rate if you have more than one child. These set amounts are all added together and this becomes your maximum amount.

Other income is then deducted from this and the figure which is left will be the amount of Universal Credit you will be paid each month. If you are in receipt of DLA the benefit cap will not apply to you. All payments should be made on a monthly basis.



Disabled Facilities Grant

This is a grant which can be applied for if you need to adapt your home for your child or young person. It will not affect any other benefits which you may be receiving. The maximum amount you can receive in England is £30,000 and Wales £36,000. If your child or young person is under 19 then the grant will not be means tested. However, if costs are over this limit, the Council has the discretion to give a further grant covering the full costs of the mandatory works.

Local Authorities also have discretionary powers to provide financial and other assistance for improvements or repairs to the home. This can be in the form of a grant, loan, labour, relocation expenses, materials or advice. Contact your local housing authority to find out how these powers apply in your area.

The Council will only pay the money once they see that the

building has been done according to the grant approval, so you may need to find a builder who can be paid at the end of the work rather than at the beginning. Unfortunately most grant applications take 6 months and the money should be received within 12 months.

Before you apply for this grant you will need to find out what work needs to be done and have some quotes ready to show the Local Authority. To apply for the grant you will need to contact your Local Authority and you may wish to ask for an Occupational Therapist visit where they can discuss further with you the adaptations you may need. They will not be able to refuse this request.

The BDFA will be able to provide you with information on some adaptations or equipment which you may need in your home. Please contact the Support and Advocacy Partner for more help and advice. You can also apply for a smaller grant of up to £1000 for small aids or adaptations to be made in your home. You can apply for this as long as it is to assist with caring at home or aids for daily living.

In Wales you could receive a grant called the 'Rapid Response Adaptations Programme'. This provides small scale adaptations in a relatively quick period of time. You will need to be referred to them from your Local Authority. For more information please see their website:
www.careandrepair.org.uk

In Scotland, if you own your home your Local Authority may provide a grant or loan for you to make adaption to your home. You should receive 100% of the grant if you are on means tested benefits and at least 80% if you do not receive benefits.

You may also be able to apply for a grant if you live in rented accommodation. Local Authorities in Scotland must provide a grant so that a disabled person has access to certain amenities, such as:

- a toilet
- a bath or shower
- a wash basin

They must also provide a grant for work which is seen as essential in meeting the needs of the disabled person. The Local Authority will decide if adaptations are essential when they do an assessment of your child's needs. For more guidance visit: **http://www.sehd.scot.nhs.uk/publications/CC2009_05.pdf**

In Northern Ireland you may be eligible for a £25,000 grant. In some cases this may be more but this is at the discretion of the Housing Executive and with approval from the Department for Social Development. Applicants in Northern Ireland should contact their local housing executive office for a preliminary enquiry form.