Help for individuals and families affected by cleft

While the NHS provides free of charge treatment for people born with a cleft, there can be many extra costs that can quickly add up.

Cleft is not considered a disability, but many of the different kinds of financial help available are not about the severity or classification of a condition, but rather the financial impact it can have on a family and/or the amount of extra care a child needs as a result. If you need to travel a long way for treatment, need lots of extra equipment, or need to miss work to bring your child to many different appointments, you may be able to get financial help.

This factsheet gives a brief overview of the main types of financial help which might be available to people affected by cleft. CLAPA cannot offer advice on how to access these or on your eligibility. We would strongly recommend that anyone seeking help contacts their local Citizens Advice Bureau or an independent welfare rights agency for professional advice.

FAQ

Can I claim Disability Living Allowance (DLA) for my child with a cleft?

Disability Living Allowance (DLA) is a non-means tested benefit, meaning it is paid because of your circumstances, not your income. There are two elements to it, care and mobility. Many children born with a cleft will have more care needs than other children the same age, e.g. feeding, sleeping, visits to hospital, speech & language therapy etc. If this is the case for your child, it’s possible they will be eligible for the care component, but you will need to demonstrate that they need much more looking after on a regular basis than other children their age.

It can be quite difficult to claim DLA, and many parents find they have to appeal before being awarded it. You or your child may need to go for an assessment, and we would strongly recommend getting specialist help from Citizens Advice or a welfare rights specialist to complete the DLA claim form.

If you’re claiming DLA for your child, you may qualify for other benefits like Carer’s allowance, extra tax credits, even disabled facilities grants for your home and VAT relief on certain items.

What’s the ‘Family Fund’?

The Family Fund is an organisation that provides grants to low-income families raising disabled and seriously ill children and young people. The Family Fund has told CLAPA that they will consider applications for financial help from families affected by cleft. They help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and family holidays together. To apply visit: http://www.familyfund.org.uk/

Can we get help with travel costs to and from hospital?

Some patients are entitled to help with travel costs to and from hospital. If you are on a low income and in receipt of certain benefits and/or tax credits you may be able to claim for travel costs for you or your child’s visits to cleft related hospital appointments. For further information please see: http://www.nhs.uk/NHSEngland/Healthcosts/Documents/hc11-april-2013.pdf
Are there other kinds of grants available?

There are many different kinds of grants available to families facing financial difficulties. A charity called Turn2Us can help you find a grant that’s right for your family: https://www.turn2us.org.uk/

What are the different benefits and tax credits available?

Find out all you need to know about benefits and tax credits here: https://www.gov.uk/browse/benefits

Useful contacts and further sources of help:

The main thing to remember about all of these benefits, grants and tax credits is that it’s up to you to claim them! No-one is going automatically award them; the responsibility lies with you to find out what you’re entitled to and claim it. Remember to always keep copies of paperwork and forms, and inform the relevant organisations if your circumstances change.

For further advice:

- www.adviceguide.org.uk from Citizens Advice.
- Disability Benefits helpline: 0845 712 3456
- www.turn2us.org.uk Charity providing info on benefits, grants and other help
- www.entitled.to.co.uk Online benefits calculator
- www.gov.uk the Government’s benefits information site. Try using their Benefits Adviser which provides information about all benefits, including disabilities.

Did you find this factsheet helpful? Please let us know what you think, or send any suggestions for future information sheets to info@clapa.com.