



# UNDRESSING DISABILITY

enhance the uk

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## Parenting Guide For parents of children with an impairment

### Summary

In the UK there are 800,000 disabled children under the age of 16, according to statistics from The Disabled Living Foundation. That's around 1 child in 20 and 99.1% of those children live at home and are supported by their families. Enhance the UK (ETUK) has undertaken a variety of research activities to bring this Parenting Guide to you. Our aim is to provide you with some useful information to help you on your parenting journey. You may be someone with a child newly diagnosed as having a disability or impairment. Or you may be pregnant and have discovered some abnormalities during Antenatal Screening. Either way, we hope this guide can help by providing some information, advice, and guidance, as well as sign-posting various other sources of information that may prove to be useful at this time in your life. For ease we have provided clickable links throughout this guide.

We are sure you'll appreciate that with there being such a wide spectrum in regards to disabilities and impairments, we couldn't possibly provide detailed information on each and every one. What we have aimed to achieve in this guide, is a wide range of information and resources, that you can then hone in on dependent upon your own situation and circumstance.

### Receiving the news

There are various moments throughout pregnancy to early years that you could be advised your child has a health condition or impairment. You can be made aware of this during routine antenatal scans, at the birth or during your child's early years development. Or your child could have become unwell or had an accident resulting in disability or impairment. All scenarios are equally upsetting and difficult.

Receiving news that your child has or could have a disability or impairment can be, understandably, earth shattering. It's natural that it can take some time to come to terms with this news. Don't be tough on yourself for experiencing a variety of emotions. Some parents describe a feeling of grief or loss initially, for not having the child they dreamed of. For not knowing what the future holds. Some parents describe feeling guilty. You must know this is normal and is a common reaction.

### Antenatal screening identifying abnormalities

If you have been advised of abnormalities during routine screening you will be referred to a specialist to discuss your situation further. You will understandably be very shocked at this point, as no one would ever imagine it could happen to them.

If screening tests predict a serious abnormality, find out as much information as you can from your consultant. You may be required to make what some feel is an impossible decision at this time – whether to terminate or continue with your pregnancy. If you are facing this heart-breaking decision, you may wish to discuss this in detail with people who can help you understand your choices in more detail. The charity, [Antenatal Results and Choices](#) (ARC) can help you by ensuring you have all the information you need prior to making a decision, without judgement or influence. It may feel like no one can possibly understand your

situation or the choices you face, but there are charities like ARC that can help you during this difficult time.

## Diagnosis

Another challenging factor can be the time it takes to reach definitive diagnosis.

There may be times where the diagnosis changes. There may be times when the diagnosis cannot be accurately made until your child reaches significant developmental milestones.

This is undeniably a difficult time, be kind to yourself, know this is not your fault and that you cannot control this situation.

## Dealing with your feelings and emotions

Undertaking your own research can help you understand that these feelings and emotions are entirely normal under the circumstances. But do not compare yourself to others, as there is no right or wrong way to feel and there are no two families on the exact same journey.

Reaching out to parents who are on a similar journey to you, or who have a child with the same condition as your child can be beneficial and provide some insight and reassurance.

It is very important to ensure you have someone to share your emotions with. If not in person, a great outlet is to record how you feel, write a journal, join a local support group.

Counselling can be a very effective way of getting the right support and guidance needed to help you manage your emotions. You can access counselling in various ways and a few routes are noted below: -

- GP Surgery – your GP can refer you for counselling.
- Counselling Directory – can help you find professional support in your area from registered practitioners.

## Useful links

Once you have received the diagnosis that your child has a disability or impairment, you will be given details for support groups specific to the needs of your child. Parents have found it helpful to connect with other useful charities, agencies, and groups at this time, both for further information and support.

We have listed below a handful of links relevant for parents of children with a disability or impairment: -

- [Social Care](#) – This Social Care and Support Guide can help with gathering information on day-to-day living because of illness or disability. It provides a number of options and where you can get support, plus details on Carers Assessments.
- [Scope](#) offer a range of support services for families.
- [Bliss](#) can provide advice and support to families with a baby in special care.
- [Local Council](#) can provide details of parent carers groups in your area.
- [Down's Syndrome Association](#) can give advice if your child has been diagnosed with Down's Syndrome.
- [Contact](#) can help with advice for families with disabled children.
- [Kids](#) - ensure disabled children from birth to 25 have the opportunity to learn, play, build friendships, gain confidence and improve their well-being.
- [Sibs](#) - is the UK charity for brothers and sisters of disabled children and adults.
- [Cerebralpalsy.org.uk](#) provides support by offering impartial information on a broad range of subjects that people affected by CP should find useful.
- [Royal Society for Blind Children](#) provide a range of services for blind and partially sighted children and young people and their families.
- [National Deaf Children's Society](#) help families give the best possible support to their deaf child every step of the way.
- GP Surgery – many GP surgeries have carers registers, ask to be added and they can keep you informed on local groups as well as provide support for you as the carer.

**Disclaimer:-** The links provided above, and anywhere within this guide are not endorsed by ETUK and ETUK have no engagement with, or first-hand knowledge of using these companies. It is advisable that you undertake your own due diligence on any companies you wish to engage with.

## Your child's medical needs

Your child's medical and healthcare needs are the responsibility of your local NHS health services. This includes any medical equipment, such as special beds, bed equipment, hoists, and aids to help with incontinence, mobility, or hearing. This is usually provided free of charge.

If your child needs regular healthcare treatment at home, your family may be supported by community children's nurses. They can also help with any treatment you need to carry out for your child, such as giving oxygen or injections.

Your child may receive a continuing care package if they have needs arising from disability, an accident or illness that can't be met by existing universal or specialist services alone.

## Ask for help

One of the most common themes from all parents we have engaged with was "ask for help". Asking for help should never be seen as a sign of weakness, and nearly every parent we spoke to reiterated this and wished they had asked for help earlier than they did.

A few suggestions of places you can access help are noted below: -

- Social Care
- Friends
- Family
- Facebook groups
- Antenatal classes
- GP surgery
- Health Visitors
- Occupational Therapists
- Specialist support groups

It's normal to worry about whether we're good parents, whether our children are disabled, or not. Did we handle that situation right? Could we have done that differently? Am I a good enough parent? In these situations, you may find it helpful to seek that guidance, support and advice from your support network, health visitor, healthcare professional, etc.

## Financials

There are various schemes in place to help parents of children with disabilities. Eligibility can vary, so please investigate further to identify what you are entitled to. Here are some initiatives that may help you financially, this list is not exhaustive, but should prove useful in identifying what funding is available: -

[Maternity Pay](#)

[Free childcare for 3-4 year olds](#)

[Shared Parental Leave & Pay](#)

[Child Tax Credits](#)

[Paternity Pay & Leave](#)

[Universal Credit](#)

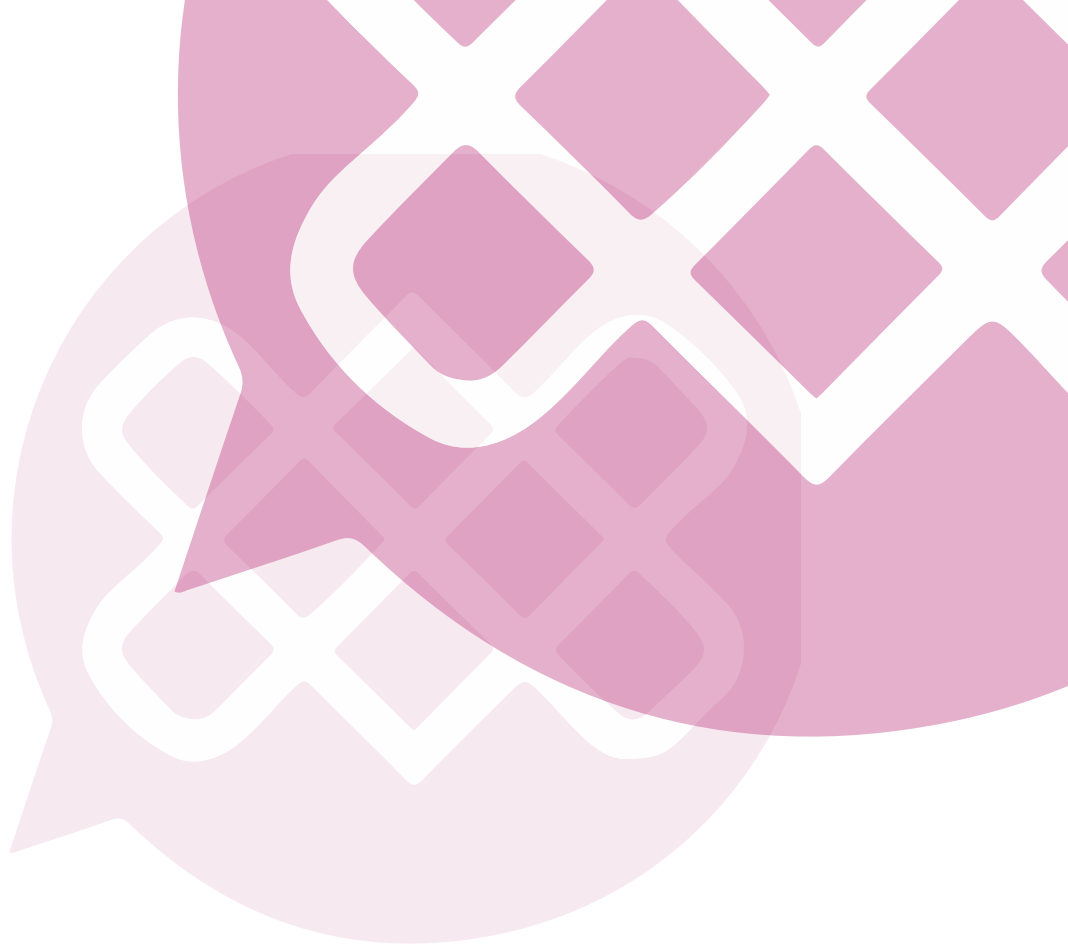
[Maternity Allowance](#)

[Disability Grants](#)

[Sure Start Maternity Grant](#)

[Various Alternative Grants](#)

[Child Benefit](#)



# About us

'Undressing Disability' is a global campaign which aims to raise standards in sexual health and sexual awareness for disabled people. Issues around sexuality and sexual frustration are frequently raised by disabled people who feel that they have less opportunity and ability to explore their sexuality than others. Through a lack of understanding, education and a general lack of services, disabled people frequently cannot access the support that would make it possible for them to make the sorts of choices about their lifestyles that most of us take for granted. As part of our campaign we run the Love Lounge, an online forum providing free advice on all things sex, love and disability. We also have free downloadable resources. As a user-led charity, our aim is to change the way people view disability, which often involves removing the 'fear factor' that so often surrounds the subject. We support businesses to be more inclusive by providing disability awareness training, British Sign Language workshops and accessibility audits, amongst other things.

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#undressingdisability



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CHANGING SOCIETY'S VIEWS ON DISABILITY