



Supporting families through a learning disability diagnosis

– a resource for
healthcare professionals

As a healthcare professional you may be required to support new parents come to terms with a diagnosis of learning disability or genetic difference. This could also be called a chromosomal disorder or genetic disorder. This can be a difficult conversation to have, but it's important to remember you have a responsibility to new parents to deal with this news in a sensitive and empathic way.

Hospital staff, including obstetricians and midwives, play a vital role to ensure that families have the most positive experience they can – right from the very start. These first interactions can help to pave the way for better care throughout a child's life. Good, positive treatment, communication and support can make a big difference.

More importantly, it also establishes the families' first perceptions of their child. A negative association with their additional needs can set back their ability to come to terms with the fact that their child's future may be different from the way they imagined it. Many families have told us this took them years to overcome. You have a vital role to play in setting them on the right path.

Unfortunately, this isn't always the experience of families currently. In a recent Mencap survey, 45% of parents reported negativity, prejudice and discrimination from healthcare professionals in the weeks following diagnosis. Many families said they felt fear, sadness and shock at the diagnosis. This clearly shows the need for more support for families dealing with diagnosis of a genetic difference or learning disability. This resource includes quotes from parents about their experiences of diagnosis and healthcare.¹

References

¹Mencap conducted a survey with 116 families about their experience of children with a learning disability aged 0-5 between 28/09/20 to 21/10/20.

Life with a learning disability

Having a learning disability is just a small part of who a child is - the disability does not define them. Every child with a learning disability is a unique individual, with their own needs. With the right support, children with a learning disability can grow up leading fulfilling, happy lives in the way they choose.

The life chances of people with a learning disability is significantly influenced by their ability to receive the right care and support in their early years. Hospitals are uniquely placed to have these early interactions and therefore to act to ensure support is in place in a timely way.

Good communication

Good communication with expectant parents is really important, particularly when supporting them through antenatal screening tests and delivering news about a genetic difference diagnosis. Parents will be processing a lot of information at this point, so it's important to be clear, to use positive, supportive language, and to be sensitive.

Words have a lot of power – think before you speak.

The way that you talk about learning disability and the things you say could have a lifetime impact on children and their families.

Check your assumptions - every child with a learning disability is a unique individual. Make sure you're not making assumptions about their life chances, and don't assume that their life is limited or will be unhappy or unfulfilling just because they have a learning disability.

Be aware of the positive aspects of the lives they will lead too. This is a child who will bring love and happiness to their family's life as well as their own individual attributes.



I was also constantly asked when pregnant if I tested to see if there was anything “wrong” with this one.

Mencap early years survey, 2020



For parents that are expecting a child with a diagnosis of Down's syndrome, they really need to look at the way they deliver the news and care post diagnosis to support parents through the pregnancy.

Mencap early years survey, 2020

Antenatal screening tests

It is important that expectant parents are always adequately supported to fully understand antenatal testing, the nature of the information it may give, and whether they want this information. As a healthcare professional you have an important role to play in supporting families to understand the screening process and not to make any assumptions as to whether they should or should not be screened.

The National Centre of Health and Care Excellence (NICE) states that healthcare professionals should explain that the decision whether to have antenatal screening tests is the choice of the expectant mother, and you should make sure that they understand what those decisions mean for them and their baby. Make sure the parents understand all the information they are given, and that they have had enough time to decide whether they want the tests or not.²

The screening results must also be treated with great sensitivity. If there is a heightened chance of a genetic condition being present in the foetus, families should receive balanced information about it. It is essential that no judgement is made about the condition or a family's decision as to how to proceed.

The information these tests can provide may help you and your team to provide the best care possible during a mother's pregnancy and the birth. The test results may also help expectant parents to make choices during pregnancy.

While healthcare staff are not genetic counsellors, it is important to be sensitive and empathetic when dealing with expectant parents. Remember, this could be an extremely difficult time for parents - they deserve to be fully informed and positively supported through the process.

Guidance for professionals on non-invasive prenatal testing (NIPT) is available - <https://www.nuffieldbioethics.org/publications/non-invasive-prenatal-testing>

References

²<https://www.nice.org.uk/guidance/cg62/ifp/chapter/About-this-information>



When I said I wouldn't test in any pregnancy I was asked did I really want another baby with Down's syndrome.

Mencap early years survey, 2020



One midwife was extremely supportive and took time to talk at scans. She was the only professional who seems to show empathy with what we thought we were facing.

Mencap early years survey, 2020

Access to counselling

Healthcare professionals should refer all new parents who receive a genetic difference diagnosis to genetic counselling. Genetic counselling could help the family fully comprehend the diagnosis of their unborn child and help them make informed choices about their future.

There are genetic counselling centres across the UK. The Genetic Alliance provides a list of services - <https://geneticalliance.org.uk/information/service-and-testing/nhs-genetic-services-in-the-uk/>

Screening pathways

NICE recommends that all new parents who receive a genetic difference diagnosis have a pathway of support mapped out, so that, when a baby is born, everything is in place for them and their parents to access the support they need³.

Information

Fewer than one in three families received the right type and amount of information from the hospital care team in the weeks and months following the diagnosis). (Mencap early years survey, 2020).

Parents are entitled to accurate, up to date and balanced advice and information. There is information available, but there is also scope for more resources to be produced with families, to help reflect their experiences too. As well as providing information yourself, you should signpost expectant parents to external organisations and support networks. This gives them the opportunity to learn more about learning disabilities, diagnosis, and the support available for new parents.

References

³NICE Guidelines (2017). Antenatal care for uncomplicated pregnancies | Guidance and guidelines | NICE. [online] Available at: <https://www.nice.org.uk/guidance/cg62/chapter/1-Guidance#screening-for-fetal-anomalies> [Accessed 31 Oct. 2017].

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There was no support after finding out our unborn baby had Down’s syndrome. All the time we were offered abortions.

Mencap early years survey, 2020

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The information was very outdated.

Mencap early years survey, 2020

A range of information is available for expectant parents and healthcare professionals:

nhs.co.uk has information on genetic differences including Down's syndrome, Patau syndrome and Edwards' syndrome

Mencap provide a range of information and resources for parents – including information on genetic differences, diagnosis and supporting children with a learning disability - <https://www.mencap.org.uk/advice-and-support/diagnosis>

Other parents and family carers can offer advice and peer support to expectant families. The Mencap online community is a space for parents and carers to share their experiences - <https://www.mencap.org.uk/onlinecommunity>

The Learning Disability Helpline offers free advice and information to families - **0808 808 1111**

Support Organisation for Trisomy 13/18 (SOFT) - provide **support** and understanding to families involved in the issues and decisions surrounding the diagnosis and care in Trisomy 18, 13 and other related genetic differences. SOFT also provide resources for healthcare professionals.
- <https://www.soft.org.uk/>

The Down's Syndrome Association has information for new parents including information and support on pre-natal diagnosis and non-invasive prenatal test (NIPT) for Down's syndrome - <https://www.downs-syndrome.org.uk/for-new-parents/>- **0333 1212 300**

The Down's Syndrome Association also provide information for maternity professionals - <https://www.downs-syndrome.org.uk/for-new-parents/>

The Fragile X Society provide information and support on Fragile X for families and professionals - <https://www.fragilex.org.uk/> / **01371 875100**



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