Children with Exceptional Healthcare Needs (CEN) Network

'What to expect' when your child has exceptional healthcare needs'

Family information booklet

This Leaflet has been prepared by NHS National Services Scotland (NSS) National Networks. Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHSScotland and other public sector organisations to help them deliver their services more efficiently and effectively. Working across professional and organisational boundaries, National Networks support the delivery of safe, effective healthcare that's designed around patients, carers and families.

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Introduction

This booklet is for families who care for children with exceptional healthcare needs. What we mean by exceptional healthcare needs is on the CEN website here nn.nhs.scot/cen/about-national-managed-clinical-networks/cen-criteria/. We want to make sure everyone receives the best care wherever they live in Scotland. We bring families and health care services together to share information, improve services, develop guidance and learn from the experience of others. In Scotland, there are around 700 children with exceptional healthcare needs. If you want to read more about the CEN Network visit the Network website at nn.nhs.scot/cen/.

In this booklet we use the term ‘parent’ to mean the child’s main carer, but we know this may be different in each family.

Being a parent

You may find out that your child has exceptional needs during an antenatal scan, after your baby is born or later in their childhood. For everyone, being a parent can bring a range of emotions, it can be a big change. You may have emotions you were not expecting when you find out your child has exceptional healthcare needs. You may also find that the people closest to you are having different emotions to yours. It is important to know that there is no ‘right way’ to respond. Knowing this can help us to feel less confused by the other person’s reaction. If you can, try to talk together about how you feel.

Parents told us about how “Unreal everything felt and having a new baby got lost in all the drama”. One family said, “Receiving cards, balloons and gifts helped us to have something of what we expected to feel at our baby’s birth.” The support of those around you can be comforting and ease what may be a stressful time for you and your family.

Parents and other family members should take care of their own health and emotional wellbeing and seek support. This could be from family or, friends or from formal counselling. You can ask your health visitor or another health professional about local psychological or emotional support services. These can be part of the NHS or provided through a charitable organisation. There are a list of support agencies on the CEN website here: Useful links – Children with Exceptional Healthcare Needs (nhs.scot).

> “Initially I reacted more emotionally to the situation while my husband was more matter of fact about it. Over time I have become more used to the rollercoaster ride that we're all on and switch into coping mode when a crisis happens. I allow myself time after each crisis to reflect on what has happened and come to terms with it.”

Time to adjust

As a parent of a baby or child with complex healthcare needs you may need time to adjust. At times, professionals may ask you to make decisions you feel you are not knowledgeable enough to make. If a decision does is not required immediately then ask them to explain your choices in a way you can be best informed. Please remember that any decisions you do make, you have made them from the heart and with your child's best interests in mind.

The process of understanding your child's health needs can take a long time. As a parent this can feel difficult, and you may feel as if you are 'in limbo'. This can be particularly true if the cause of your child's health needs is unknown or their condition does not have a name. The professionals involved in your child's care are doing their best to support you in these difficult times.

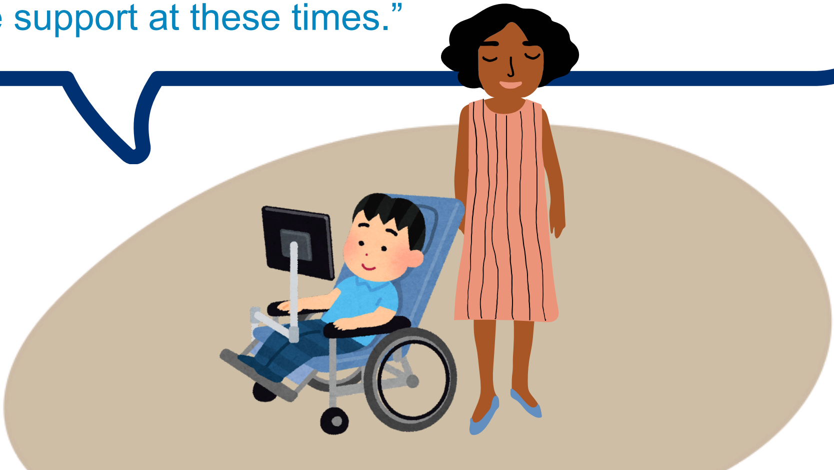
It is important for you, your family, and your child to share the good times too. Finding what they enjoy and having fun together is important for you both and for the others who care about you.

Some practical things to think about

Here are some tips which may help you as you learn about your child's condition:

- write information down
- record conversations
- ask for information to be repeated or ask for a different explanation if you don't understand
- identify a professional you can contact if you can't remember something or to check what you've understood
- ask to be included in all correspondence about your child
- take someone with you, it can help to have someone else there if you are given important information about your child's condition(s)
- be kind to yourself.

> "We had a lot to learn and cope with in the early years. At the age of 11 my son had his first seizure and at the age of 17 had his first hospital admission due to dystonia. These new things were hard to come to terms with. I was probably regarded as a parent who coped but I needed more support at these times."



There could also be practical changes both at home and in hospital, some are noted below:

- you may have lots of appointments to attend that need travel and organisation. It can be helpful to add these to a diary
- your child may need to spend time in hospital, making a packing list may help you prepare for this
- you may need to learn healthcare treatments, there are professionals who will help you with this
- your child may need medical equipment and supplies at home. These can take up a lot of space and it can be helpful to plan for this
- you may need a home assessment to see if your home needs any changes to suit your child's needs
- health care professionals and carers may be regular visitors in your home- they will always treat you and your house with care and respect. These people may not be the same each time
- you may have to complete paperwork and apply for benefits to support you in caring for your child. There are advocacy organisations who can support you to do this
- if you are employed, you may need to change the way you work, it can be helpful to talk to your employer about this. You may now be eligible for certain benefits which will support you financially.

People who may be involved in caring for your child

Consultant Paediatrician	Sometimes known as ‘Consultant’ or ‘Paediatrician’. They are responsible for medical care in hospitals. Children with exceptional healthcare needs may have multiple consultants specific to their needs e.g., neurology, respiratory. The Consultant advises on the child’s condition, treatments, and prognosis.
Community Paediatrician	A Consultant who specialises in the care of children in the community setting (at home), often responsible for developmental assessment and care.
Consultant Neonatologist	A Consultant who specialises in the care of sick and premature babies.
Community Children’s Nurse (CCN), Specialist nurse, Advanced Nurse Practitioner	Children’s Nurses who can assess children at home, link with hospital services and give advice to parents/carers. The CCN may have a specialist role for example for respiratory or epilepsy.

General Practitioner (GP)	GP’s provide healthcare for the whole family through Primary Care. Every child should be registered with a GP.
Health Visitor or Family Nurse	Health Visitor is a nurse who supports the health care of young children and the needs of parents. Family Nurses work with some young parents to provide help in parenting skills until age two when the Health Visitor takes over as GIRFEC named person until school entry.
Housing	Housing deal with home adaptations and allocation of accommodation for the local authority (council).
Neonatal Nurse/ Advanced Neonatal Nurse Practitioner (ANNP)	Neonatal Nurses and ANNP’s will be aware of protocols and guidelines used in local neonatal unit. They advise on care until handover to Community Nursing team, support early feeding, baby massage and infant mental health/attachment.
Physiotherapist	Physiotherapist advise on posture, motor function needs and clearing airway secretions.

Speech and Language Therapy	Speech and Language Therapist assesses swallow safety, baby’s development of oral skills for feeding and speech and communication.
Dietician	Dietician assesses nutritional needs and how these can be provided including any need for tube feeds or additives to promote improved calorific intake and growth.
Pharmacist	Pharmacist dispenses prescribed medications, advises on effects of drugs and suitable formulations for the individual.
Psychologist	Psychologist specialises in mental health for the baby Child and Adolescents Mental Health Service (CAMHS) or parents/carers.
Health Play Specialists	Health Play Specialists trained in assessing and adapting developmental play needs of children with medical conditions and disabilities.
Social Work	Provide holistic support around the family's needs these may be from your local authority or a charitable organisation.

Occupational Therapist	Occupational Therapists (OTs) assess the needs for the individual’s daily care in the home, may not be available for inpatients.
Dentists	A Dentist will help with your child’s regular mouth care and any dental problems. Care may be provided at a local dental practice, through public dental services, or at a hospital, depending on your child’s needs and where you live. A Dentist will monitor your child’s mouth and teeth as they grow. They will work with you and other healthcare professionals to support good mouth care, including a tooth-friendly diet and safe toothbrushing. They will also check for cavities or gum issues, and provide treatment when needed.

What to say when you don’t know what to say

Growing up can be a challenge, but it can be even harder if your child looks different. The charity Changing Faces have several resources to help you if your child has a visible difference. From supporting your child, to looking after your own wellbeing. You can find the resources on the Changing Faces website here: For Children, Young People & Parents | Disfigurement Advice (changingfaces.org.uk).

“I am comfortable sharing info about my son and how his situation has changed his life and ours. I openly tell people that I am a carer and share hints and tips. I tend to find that others do the same and we learn from each other.”

“My son is non-verbal and relies on me to be his voice. I have had to be the assertive parent who speaks up in meetings and challenges things. There's no point in being aggressive - just be sure of your facts and your rights and talk calmly and confidently. Know that your opinion matters just as much (if not more in some instances) than the professionals.”

“It would have helped to have a clearer understanding of the roles and responsibilities of the various people who became part of our life. Having this info helps you to direct your many questions to the right person.

Nowadays I use groups on Facebook that are relevant for my son's conditions. Parents on these groups understand what we're dealing with. However, as with any social media, you need to be careful about the content as it's not always accurate.”

“We've lost touch with the majority of the friends we had. Friends wanted to fix things and when they couldn't understand the situation, they didn't know what to do. They tended to find the conversations awkward when the news wasn't good and we found ourselves pretty much on our own. Our friendships are now with parents in a similar situation, but we really do miss our other friends. It would be great if friends realised that they don't need to take on everything that we're dealing with, they just need to continue to care about us.”

What the future holds

Some children’s lives are shorter because of their condition. Parents told us that finding out their child’s health needs would affect how long they lived was upsetting and confusing. Parents told us they felt unsure on what the words ‘limited life expectancy’ meant. This left them fearful that their baby or child’s death was going to be very soon. They also said that words such as “life-limiting”, “life-shortening” and “not compatible with life” also left them unsure on what to expect.

What the future holds

Professionals may know how long other children, with the same condition as your child live for. This does not mean they know how long your child will live. You need to remember that every child is different with their own timescales. The most important thing is to seek support so that however short your child's life is, you can support them along that journey.

Moving on to education

There may be a time when your child is preparing to go to nursery or school. Education usually begins at the age of three in Scotland through an early years placement. Some children may also qualify at a younger age through the Scottish Government's "Eligible Twos". The type of nursery or school that your child may attend can differ depending on your local area. In some areas, a specialist nursery or school for children with additional support needs may be available. In other areas, children with additional support needs attend their local mainstream school with support. Even if there is a specialist school available in the area, some parents and carers may choose to send their child to their local mainstream school. Healthcare workers who know your child and professionals from education can help support you with this decision. Support organisations for school placements include- Enquire, you can visit their website here - Enquire - The Scottish advice service for additional support for learning.

Summary

We hope that this booklet was helpful for you and your family and puts some of your potential worries as ease. There are a number of support agencies available to you a list of these is on the next page. If you have any feedback

Support Organisations

PAMIS - Provide support for people with profound and multiple learning disabilities (PMLD), their family and carers and interested professionals

Contact - A national charity for families with disabled children.

Family Fund - The Family Fund is the largest provider of grants to low-income families raising disabled or seriously ill children and young people across the UK.

Sibs - For brothers and sisters of disabled children and adults

SOFT UK - For UK families affected by Patau's syndrome (trisomy 13), Edwards' syndrome (trisomy 18) and related disorders.

Carers Trust - Carers Trust Scotland is the largest provider of comprehensive carers support services in Scotland.

Together for Short Lives - UK charity for all children with life-threatening and life-limiting conditions

The Office for Rare Conditions offer information and support to those affected by conditions that are not common or may not yet even be diagnosed.

Children's Health Scotland - Dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children and young people within our healthcare system.

Kindred - provide advocacy and information on services to children with additional support needs and their carers

ALISS (A Local Information System for Scotland) - is a service to help you find help and support close to you when you need it most

A number of further support organisations can be found on the CEN website .