

# Children with Exceptional Healthcare Needs

National Managed Clinical Network

## What to expect when your child has complex needs

Just found out your baby  
or child has complex  
healthcare needs? What  
could this mean for you  
and your family?



# Aims of the booklet

It is hoped that this booklet will give you some idea of what might be involved for you as a family when your child has complex healthcare needs. It explains about some of the **feelings you might have** and how these feelings might make you or other family members react.

This booklet cannot cover every situation or set of circumstances, not least because we are all individual and experience our lives in different ways. However, when talking with parents about their children some **shared themes and experiences** did emerge.

The contents of this booklet are therefore informed by the real, **'lived' experiences** and quotes of parents who helped with this project. It may also be helpful to share this booklet with wider family and friends so that they can better understand what you are dealing with and how they can support you.

**“At first you will wonder how on earth you will manage, but you will find strength you never knew you had and begin to build your ‘new normal’ and a network of support”.**

## The booklet looks at some of the following key areas:

- Feelings and emotional impact
- Being a parent
- When your baby is born with complex needs
- Discovering your child has complex healthcare needs after birth
- Time to adjust
- A shorter life
- Some of the practical aspects you may have to deal with
- Who might be involved?
- What might happen when you get home?
- What parents told us worked for them?
- Organisations that offer support and information

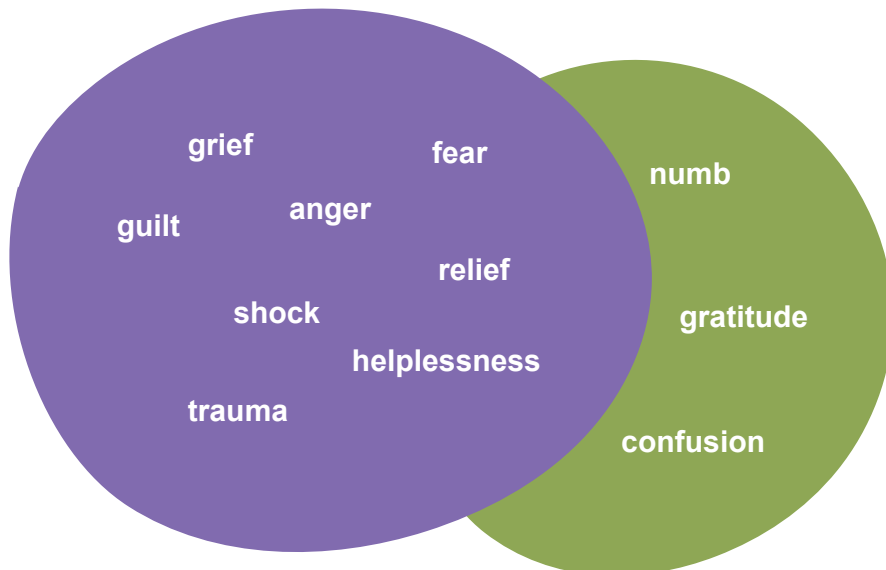
## Thanks & acknowledgements

This booklet has been informed by interviews with a number of parents across Scotland who generously shared their experiences and thoughts. Several professionals from health, social work and clinical psychology were also interviewed. This edition has been revised and updated and the Exceptional Families Project thanks everyone for their contributions and support in developing this booklet.

## Feelings and emotional impact

Every parent who we spoke to in creating this booklet talked about the emotional impact of finding out that their baby or child was very unwell. Some could recall so clearly their particular feelings at the time. One father talked about there being “**so much emotion I thought it would overwhelm us**”.

**When your baby or child is very unwell you may feel a whole range of emotions such as:**



All of these feelings are **natural**. Some feelings will be more powerful than others. Parents talked about having “moments of great clarity” whilst others experienced “a fog, nothing made sense, one minute I thought I understood then the next my mind was fuzzy”. Often, you can find yourself going from one set of feelings to another, all within a short space of time. Some feelings may make you feel more uncomfortable than others, but they are all an understandable response to what is going on.

People around you have to recognise that their responses and behaviours can add another pressure to what you are already experiencing.

“I often felt I was putting on a show...it was exhausting but I felt I had to do it to avoid judgement and also to keep some control...If I admitted I was struggling then medical staff might take over”

## Being a parent

Sometimes we can be surprised by our reactions to things and the feelings that we have. We can also find that the people closest to us seem to be having different feelings to ours and this can be confusing or upsetting. Different parents and carers won't necessarily respond in the same way to a situation. It is very important to understand that there is no 'right way' to respond and that each of us will react in our own way. However, knowing that we can feel differently from each other can help us to feel less confused or hurt by the way the other person is reacting.



**"I am not saying I dealt with it all better, but my partner was so shocked. They closed off from me, from everyone really. I know now how alone they felt but it was a real struggle at the time as I felt I had to deal with everything myself and because of that I stopped sharing my feelings with them"**

When we are afraid or confused it can be difficult to keep communicating openly with each other. If we can try to express our feelings and ask the other person about theirs; we are less likely to find our imagination taking over, to misread situations or to think something is negative when it isn't. This can help to prevent us from panicking and becoming highly anxious.

We need people around us to be supportive, not judge us and to acknowledge what is happening.

“

**My partner was the only other person who knew what this felt like. It was hard sometimes but I had to keep talking to him so as not to feel so isolated"**

Not everyone will feel in these ways. Some parents describe 'feeling nothing at all'. When we are in shock and can not take in what is happening, this is a protective mechanism that can enable us to come to terms with things in a more manageable timescale.

The key message here is that whatever you are feeling is understandable and valid. You are in a very difficult situation. It is important to take time to look after your own health and emotional wellbeing.

**Try to be kind to yourself and to each other.**

## When your baby is born with complex needs

As a mother you may have gone through a very difficult pregnancy. You may or may not have known in advance that your baby had complex healthcare needs. Your labour and the birth may have been very traumatic. All of these experiences are very difficult to manage, you will be very tired, your body is flooded with hormones and your life has been changed forever. This is true for all mothers but especially so when a baby is born with complications.

As a father you may have seen your partner in pain. You may have been asked to make unplanned for decisions and at times felt powerless and afraid. You may also be in shock and confused by what has happened.

It is important that family and friends celebrate your baby's arrival. They may not know how to respond if your baby has been born with difficulties and be struggling with their own feelings of upset and distress. Your baby's birth should be acknowledged. No one should feel they have to say 'sorry' for the birth of your baby.

Parents talked about how "unreal everything felt and having a new baby got lost in all the drama". Receiving cards, balloons and gifts helped them to have something of what they had expected to feel at their baby's birth.

“

Getting to her first birthday was a cause of celebration – balloons and champagne. By her 5th birthday I came to accept that there could be many more birthdays”.

## Discovering your child has complex healthcare needs after birth

You may have thought your child was okay or at the very least their poor health and delayed development was not serious. To discover that they have complex healthcare needs and that this will have an impact on their day to day living and maybe even the length of their life, can be profoundly shocking and emotionally upsetting.

It can take time to make sense of what is happening and the information you have been given. If there are two parents present, the understanding of what is happening and what it means for your child will not necessarily be shared. You may of course not have a partner and be dealing with all of this by yourself. Whatever your circumstances there will be particular challenges.



## You may need to do a number of things including:



Sometimes we can believe that our personal responses to situations are the 'right way' to be and are upset by how others respond or behave. This can make the situation more challenging for everyone, so knowing that each of us finds different ways to express what we are feeling can be helpful.

“ People telling me 'what they would do' or 'that they couldn't do what I have done' didn't feel very helpful.....”

“ I had no time to be sad. I had to cope, I was her mum and no one else would do as good a job. What use was I if I couldn't get out of bed in the morning?”

“ I was lucky to have a friend who suggested things to me but mainly she just listened”

## Time to adjust

You will need time to adjust and to make some sense of it all. However, sometimes you don't get that time. You can be asked to make decisions very urgently, decisions you have little time to process and you can feel unqualified to make them. Whatever decisions you do make, remember you have made them from the heart and with your child's best interests in mind. For all the medical advances in knowledge there is still a great deal we do not know and understand. Often the process of investigating your child's health takes a long time, sometimes months, sometimes longer. This can feel very difficult, as if you are 'in limbo' and the uncertainty can feel paralyzing. This can be particularly true if the cause of your child's needs is undiagnosed, whether for a short time or indefinitely. You, and the people around you, are doing their utmost to support you in often heart breaking circumstances.

If your child is older when their complex needs begin to impact on their life and yours, then you need space to adapt. Of course they are the child you know and love but coming to terms with what will be involved in caring for them – medication, equipment, therapies and procedures should not be underestimated. Neither should the grieving for a future that may be different to what you had imagined.

You may have other children and find you're struggling to meet their needs as well and then feeling guilty. Talk with the professionals involved about what you want to share with your other children about their sibling's condition and what support they can be offered.

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He is still that bright boy, a marvel really....But now he is on oxygen 24 hours a day now and has 16 different medications to take”.

## A shorter life...

Some children's lives will be shorter because of their condition. Parents said that being told their child's complex health needs would limit their life expectancy was profoundly upsetting and confusing.

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Grief began when we were told of the possibility of early death”

However, many parents described being uncertain what the words 'limited life expectancy' meant and being left fearful that their baby or child's death was imminent.

“

We were determined that she would see her first birthday. She did.....and then we did not know what to do next because we had understood that this could not happen”

It is important that it is clear to you what the medical staff mean, if not you must ask them to explain to you. If the doctors do not know the answers it is better that they say so and acknowledge how difficult this may be for you. They may know from experience, how long other children with the particular condition may live for, but this does not mean they know how long your child will live. You will need time and maybe space to make sense of what they tell you, sometimes asking the same questions several times as you work out what this means for you and your family.

“

Another mother said to me ‘your daughter will die sometime but try not to focus on that now and know you will deal with it when it happens’ ....I found this really helpful and her death stopped being my waking thought”



## Some of the practical aspects you may have to deal with

Alongside the emotional experience of having a baby or child with complex health needs there will be practical implications for you and your family.

### These can include:

- having lots of appointments to attend
- spending a lot of time in hospital
- having to give up employment to care full time, reduce your hours or change the nature of your employment
- learning to provide healthcare for your child
- needing equipment such as monitors and hoists in your home
- making adaptations to your home or moving to a different one
- having nurses, carers and therapist providing care in the home
- having to apply for benefits and complete lots of paperwork

For some parents dealing with these practical aspects can be helpful in managing day to day, giving them a focus and sense of control. However, even the most organised of us can find the number of people and services involved overwhelming.

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I am a ‘doer’. I need to be in charge and very quickly I learned how to set up the feeding pump. I even took training in resuscitation in my stride.....but when he was about two years old, it all came crashing in and I wish I had asked for help earlier”



“

I remember when I had my first baby, it felt a bit frightening as well as exciting there was so much to get organised. Lots of the other mums seemed to feel the same though. This felt so much harder.....I never felt I got on top of anything before the next thing hit me”

For other parents, juggling the demands of family life and the additional tasks that arise when a baby or child has complex health needs is hugely stressful. Any sense that we are being viewed as ‘not coping’ can make us feel judged and add to the stress. It can also block us from being able to accept the support we need.

It is important that the people supporting us understand that we may need time and space to take in the information we are being given. It is not always obvious to a parent, for example, that an aspect of their child’s condition will require an adaptation to the home. Therefore, when a professional is discussing equipment or respite with you they need to fully explain the reasons for talking to you about these things.

You may also need to do some research yourself and talk with a support organisation like Kindred, to find out what services are available to you.

“

Sometimes parents can assume that the professionals involved would tell me everything I needed to know. If they didn’t tell me about something then I assumed that it wasn’t ‘for me’. I found out about the Family Fund from another mum and she had to convince me that I could apply. This made me feel quite angry actually”

## Who might be involved?

It is likely that when you are reading this booklet, you will have already met lots of people who are involved with your baby or child. As well as consultants, nurses and therapists you will probably later be introduced to workers from social services, voluntary organisations and education staff.

Just getting to grips with who they all are and what it is they do can be hard enough. The fact that they are in your life because of your baby or child’s complex needs can make you feel unsure about them. Professionals need to make clear to you why they are involved and what their involvement means for your family.

Try to work with the professionals who become involved with your family and help it to be a collaborative process. Of course, the professionals have a responsibility to ensure that they work with you in ways that are helpful to you too. These relationships can be very important for you and your family but it can be difficult sometimes for everyone to get the right balance.

“

She was excellent, very responsive, and efficient and had a good pastoral role. She was real and kind and would listen to my fears. She had great respect for the enormity of the task we were taking on”

## What might happen when you get home?

Many of the services that can support your family will be available once you are at home. For this reason these are called community services and in addition to health professionals these can include social care, educational professionals and voluntary organisations. You will probably still have regular contact and input from the hospital but depending on your baby or child's needs a lot of the input will be at home.

Having people in your home can be quite challenging. Parents talk about feeling 'invaded' and 'exposed'. Unlike parents of typically developing children your parenting can feel under regular scrutiny as a range of professionals visit you, often on a weekly basis. Professionals understand that they are essentially guests in your home but some will be better than others in managing this sensitively.

Depending on your baby or child's healthcare needs, arrangements may be made for nurses and carers to look after them through the night. Whilst the purpose is to enable you to sleep this can feel awkward and take some getting used to.

## What parents told us worked for them

Parents identified things that they found helpful and things they believed would have helped them in the early stages. They wanted to share these with parents who find themselves in similar circumstances.

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**Give yourself time to get to know your baby. Ask for space and time with your partner or with a friend”.**

Some parents find it very useful to talk to other mothers and fathers. Other parents prefer to find their own way, sometimes contacting support organisations when they have a question or concern.

Medical and nursing students need to learn but if you do not want them in the room when you meet with the consultant do say so.

Ask everyone who comes to see you who they are and why they are involved. Do not be afraid to do this each time until you feel sure who everyone is. You are having to deal with a lot of information and should not be expected to take it in straight away.

Sadness, when there are complications for your baby is an understandable reaction but you must look after your own health. Assumptions can be made about what you as new parents are experiencing. Ask the Health Visitor or your GP to check you for post-natal depression; don't assume that this will always be considered. It is important that the physical and mental health of all the family needs to be monitored. These professionals can be effective advocates for you and your family, if they know what is going on for you all.

If you feel you are being given 'mixed messages' – one medical person says one thing and another seems to contradict them, tell them this. There can be good reasons for having different views but it is important that the professionals work this out between them.

“

I would have welcomed another mother visiting to talk about the reality and to say look I am ok and this is what you need to look for and ask about”.



“

We were given a room away from the main ward this was really helpful as we got some privacy and time to be together as a family”.

“

The consultant handed us some written information for us to read through after he had talked with us so we could come back to him with questions. He also gave some website references that he knew were okay that we might want to look at”

“

The nurse asked us to tell her what we understood she had told us about our son's breathing. By doing this we realised we had heard different things and were able to sort it out there and then”

“

The community paediatrician took my concerns seriously. Her support and belief in my knowledge of our child was very helpful.....she appreciated the importance of how we were told as well as what we were told”.

“

We had never really spent any time in a hospital before. Everything about it is unfamiliar and by its very nature, you are in it because something has not gone to plan. It was so confusing and at times frightening to be here”.

Hospitals and other professional settings can be overwhelming places. There are different levels of decision-making but it can feel confusing and frustrating. Do not be afraid to ask the professionals how their systems and processes work.

Your baby or child may need help with their health and mobility. This does not always mean that they will have difficulty with their learning or development. Professionals need to ask you what your child understands and communicate directly with your child however complex their health needs are.

It is often possible for professionals to combine visits. If it suits you to manage the diary, you can make or at least suggest best times for home and outpatient appointments. Having conversations with the professionals and describing your particular circumstances helps everyone to work together well.

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A psychologist was part of the team on the ward, this meant we did not have to ask to talk to someone, emotional support was offered as part of the support to all families. She talked with us about what we were going through. It was such a relief to have her acknowledge that ‘of course’ we would feel confused, anxious, afraid, guilty, sad whatever and that it would ‘naturally’ have an impact on us all. That acknowledgement was so helpful”.

“

For all the difficulties our son has to deal with I celebrate the sheer joy and happiness of having such a wonderful child who brings so much to the world”.

Asking for and accepting support can be difficult but getting emotional support from a skilled listener can help you to adjust and adapt to what is happening to your family.

## Organisations that parents have found useful

**Contact** – “Finding out your child has a disability or medical condition can be difficult and bewildering. Contact a Family helped us to find other parents, information and advice”

Tel: 0131 659 2930

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

**PAMIS** - “works with our whole family providing lifelong support, this has been invaluable especially at times of transition”

Website: [www.pamis.org.uk](http://www.pamis.org.uk)

**Kindred (Advocacy)** - “our advocacy worker listened, helped fill in forms, came to so many meetings and advised us every step of the way”

Tel: 0800 031 5793

Website: [www.kindred-scotland.org](http://www.kindred-scotland.org)

**The Family Fund** - “the funds that they gave us whilst we were in hospital and away from home made a real difference, not just the money but the recognition of what we were going through”

Tel: 01904 550055

Website: [www.familyfund.org.uk](http://www.familyfund.org.uk)

**SWAN UK** – “it was such a relief to have contact with an organisation that understand the particular difficulties we faced in our child not having a diagnosis”

Tel: 020 7831 0883

Website: <http://www.undiagnosed.org.uk>

**SOFT UK / Unique**– “I do feel that it is so important that families are given the details of organisations like SOFT/Unique. These organisations help those who are dealing with the shock of a Trisomy 13/18 diagnosis to feel that they are not alone”

Tel: 0330 088 1384

Website: [www.soft.org.uk](http://www.soft.org.uk)

**Childrens Hospices Across Scotland (CHAS)** – “without our visits to Rachel House (CHAS) there would have been no break for us”

Website: [www.chas.org.uk](http://www.chas.org.uk)

**Children’s Health Scotland** - “Having a baby sister with a complex congenital heart condition requiring lengthy hospital stay and complex surgery was very traumatising for her 4-year old brother. I don’t know what we would have done without the hospital play support for her brother and support and information on the baby’s condition which included signposting to the local welfare rights adviser and liaising over travel and accommodation for treatment far from home”

Tel: 0131 553 6553

Website: [www.childrenshealthscotland.org](http://www.childrenshealthscotland.org)

The above is not a comprehensive list but are the ones shared with us by the families who contributed to the development of this booklet. For further useful links please go to the **CEN NMCN website**: [www.cen.scot.nhs.uk/](http://www.cen.scot.nhs.uk/)

# Children with Exceptional Healthcare Needs

National Managed Clinical Network

**Strengthening specialist services for children in Scotland with complex and exceptional healthcare needs.**

- We work collaboratively with health professionals, social work, education specialists and the voluntary sector to share good practice and improve services.
- We support and drive service improvement.
- We enable healthcare professionals and their families to work together.
- We develop a range of educational resources and materials.

# My Contacts



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