

Organisations that parents have found useful

"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."

<http://www.cafamily.org.uk>

"PAMIS works with our whole family providing lifelong support, this has been invaluable especially at times of transition"

<http://www.pamis.org.uk/>

"The Family Fund's Adviser came at just the right time. She listened, told me about other organisations that would help me, and made sure I was aware of the financial help available. She was my lifeline that day."

<http://www.familyfund.org.uk>

"Action for Sick Children Scotland's literature was great. It enabled me to explain to my son what he should expect. It also encouraged us to ask questions"

<http://www.ascscotland.org.uk>

"Our KINDRED Advocacy worker listened, helped fill in forms, came to so many meetings and advised us every step of the way."

<http://www.kindred-scotland.org>

"Without our visits to Rachel House (CHAS), there'd be no break for us."

<http://www.chas.org.uk>

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

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

<http://www.rarechromo.org>

Thanks & acknowledgements

This booklet has been produced by Claire Edwards, a training consultant and parent, together with the NMCN CEN. Thank you to all the parents and practitioners who generously shared their experiences and contributed to the Early Expectations project.

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Early support and early expectations when your child has complex needs

Finding out your baby or child has complex healthcare needs, what might this mean for you and your family?



This booklet has been developed by the National Managed Clinical Network for Children with Exceptional Healthcare Needs (NMCN CEN) in response to parents' early experiences when their baby was born with complex healthcare needs or when health issues developed in early childhood.

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"The trauma of our situation was made more so by the reactions of some of the people around us, their responses and comments...we looked to them for calmness and reassurance but we were met with their distress and panic"

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 includes comments about some of the feelings that 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.

Feelings and emotional impact

When your baby or child is very unwell you may feel a range of emotions. These can include –



or development. Professionals need to ask you what your child understands and communicate 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 appointments.



"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"

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.

"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"

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.

"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"

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. The physical and mental health of all the family needs to be monitored. They can be effective advocates for you and your family if they know what is going on.

"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 were told"

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.

"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 the systems and processes work.

Your baby or child may need help with their health and mobility. This does not mean that they will always have difficulty with their learning

All of these feelings are natural. Some may make you feel uncomfortable but they are all a response to what is going on.

People around you have to understand that their responses and behaviours are often adding 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. Mums and dads will not 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 and 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. When this happens we can misread situations, think something is negative when it is not and become panicky.

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 slowly come to terms with things.

The key message here is that whatever you are feeling is understandable. Try to be kind to yourself and to each other.

When your baby is born

As a mother you may have gone through a very difficult pregnancy. You may have known in advance that your baby had difficulties or you may not. Your labour and the birth may have been very traumatic. All of these experiences are very difficult to manage and you will have been 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 witnessed your partner in pain. You may have been asked to make difficult 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. But your baby's birth should be acknowledged.

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

You may have thought your child was okay or at the very least their poor health and development was not serious.

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 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 supported them in the early stages. They wanted to share these with parents who find themselves in similar circumstances.

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

"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"

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.

"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."

"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"

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

It is important that the people supporting us understand that we need time. It is not always obvious to a parent that, for example, an aspect of our child's condition will require an adaptation to the home. Therefore the reasons why a professional is discussing equipment or respite with you needs to be explained.



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.

"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 that reason these are called community services and in addition to health professionals can include social care 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

To discover that they have problems 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 distressing.

It can take time to take on board what is happening and what you have been told. 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 -

- Spend time with your partner or another family member
- Cry alone or with others
- Take time 'to let it sink in'
- Spend time with your child
- Be angry 'at the world' or at 'the messenger' (the doctors and nurses)
- Want to ask lots of questions
- Ask to be told everything again
- Want time alone
- Shout at the people closest to you

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 'they couldn't do what I have done' didn't feel very helpful"

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

"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."

Time to adjust

You will need time to adjust and to make some sense of it all. Often the process of investigating your child's health can take time, sometimes over a three month period, often longer. This can feel very difficult, as if you are 'in limbo' and the uncertainty can feel paralyzing.

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.

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

You may have other children and find yourself struggling to meet their needs and 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.

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.

“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. You will need time 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 issues 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

having to give up employment to care full time

learning to provide healthcare for your child

adaptations to your home

needing equipment such as monitors and hoists in your home

nurses or carers providing care in your home

For some parents dealing with these practical aspects can be very 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.

“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 it all came crashing in and I wish I had asked for help earlier”

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.

“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”