

# PARENTS SUPPORT GUIDE



0-4  
YEARS

CARING  
FOR A CHILD  
WITH A RARE  
CONDITION

Many parents remember the days and months following the moment they discovered their baby had been born with a rare condition, as being the most difficult stage in their child's life.

They found themselves not only having to adjust to a different experience than the one they were expecting, but also being concerned about what the future would now hold for themselves and their baby.

At the same time, they had to absorb new and complex information, whilst trying to cope with the many varying and conflicting emotions they felt.

We hope this guide will help you begin to process and understand what you are experiencing at this time, as well as providing you with some practical strategies and suggestions to help you and your baby throughout these early years.

We are here to guide and support you in whatever way is right for you.



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## FINDING OUT ABOUT YOUR BABY'S CONDITION

- Discovering your newborn baby has a rare condition is a shock for every parent and you need time to process and adjust to what has happened.

Being given accurate information about the rare condition is key to this adjustment.

Some parents are informed about their baby's condition in a clear and considerate manner which is then followed up with offers of support. Other parents' experiences may have been less helpful leaving them feeling confused, due to either a lack of information or overwhelmed by the information provided.

This can cause and increase feelings of anxiety and helplessness, so you may wish to gain accurate information for yourself about the rare condition, its management, and possible treatments.

Unfortunately, there is still incorrect information on the internet about rare conditions, so we recommend you initially use our websites (listed at the end of this document).

## ANNOUNCING YOUR BABY'S BIRTH

- Announcing your baby's birth can cause anxiety if you are unsure what to say about your baby's rare condition or whether to say anything at all. Before family and friends meet your baby, it may be helpful to share a little information

first, so they have some awareness of the situation. As well as helping them, it may also ease your own worries about other people's reactions to your baby being born with a rare condition.

Some parents send out a birth announcement card which includes a photo of the whole family; their baby's name; date of birth and weight. Keeping it simple, you can also include your baby was born with a rare condition, what it looks like and how it affects your baby. It may be appropriate to include one way in which your baby is similar to you.

### EXAMPLE

*We're delighted to announce the birth of our daughter Annie Rose. Born 8th May 2021, weighing 4350 grams. Annie has a birthmark on her cheek. Once we have settled in at home, we would love to see you.*

*LOVE FROM JOSH, REBECCA AND BABY ANNIE*

You may prefer to tell people over the phone or in person before they meet your baby. Again, it helps to mention things other than just her appearance or condition so your family and friends can get to know her.

### EXAMPLE

*"I am looking forward to seeing you. I just wanted to let you know Sabine's right arm has a large birthmark on it. It can be bit shocking when you first see her, but we are getting used to it now. She's also got cute dimples in her cheeks and I can't wait for you to meet her."*

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## YOUR FEELINGS

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Having a baby with a rare condition triggers difficult, unexpected and powerful emotions.

- Shock
- Devastated
- Confused
- Grief
- Overwhelmed
- Disbelief
- Responsible
- Repulsed
- Numb
- Proud
- Angry
- Guilty
- Scared
- Isolation
- Hope
- Shame
- Disappointed
- Love
- Pleasure

You may have experienced some of these feelings after the birth of your baby and you may have been surprised by the strength of these feelings. It can help to recognise and accept they are part of the process of adjusting and coming to terms with your baby's appearance and unexpected medical needs.

Parents can also feel guilty about having such feelings but be reassured they are shared by many others – they are normal and understandable. It is also not uncommon to swing from one feeling to an opposite feeling, for example from joy to devastation; from grief to hope; from shame to pride.

Some parents describe being stuck in the negative emotions of anger or self-blame and unable to move forward. Other parents speak with us about how they find it hard to look at or hold their

baby. Others say they feel embarrassed or ashamed of their baby. If you are struggling with these very difficult feelings don't be hard on yourself. Try to think about your baby in terms of something other than their appearance or rare condition. For example, when you look at your baby you can think, "S/he is alive. What a miracle." or "S/he seems so peaceful." or "S/he is so lively." Remember, you can have mixed feelings about your baby. It doesn't mean you don't love him/her.

It is important to try to talk to someone about how you are feeling. If you think your partner, your family or your friends can listen to you and accept your feelings at this time, talk to them. However, many parents tell us they find it hard to talk with other family members or friends because they think their feelings are shameful or wrong or makes them sound like a bad parent. Again, it's important to remember the way you are feeling is common amongst other parents in similar situations.

It can be very helpful and reassuring to talk to someone who has been in this situation and understands. It can be liberating to be able to express your feelings openly about having a baby who has a rare condition.

Being able to talk through your experience and how you are feeling is key to beginning to adjust to what has happened, which in turn will enable you to start moving forward and settle into life with your new baby.

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If these feelings persist over a considerable period of time you could seek the help and advice of your General Practitioner, which may include signposting you to specialist mental health and wellbeing support.

## CARING FOR YOURSELF

- Often parents can be so thrown by their unexpected experience and the whirlwind of emotions that accompanies it, they forget to take care of themselves. Remind yourself that the more you take care of yourself, the more you will have the energy needed to look after and care for your baby. Take the time to have a soak in a hot bath, go for a coffee with a friend or get a hug from a loved one.

Ask others to help out by making meals for your family or doing the washing for example, and if you have other children having them round to play or for a sleep-over etc. People will want to help you so whenever this is offered take it up, as this will give you some rest and help ease some of the pressure and stress you may be feeling.

## CARING FOR YOUR BABY AT HOME

- It is normal for new parents to feel uncertain about how to look after a newborn baby when they first bring them home – your midwife or health visitor can offer general advice and support.

However, not only do you have a tiny baby, but as your baby has been born with a rare condition you are in a stressful situation which brings its own unique challenges. If you feel anxious about caring for your baby in relation to their rare condition, you can always contact patient support organisations for more specific advice and support.

## GETTING SUPPORT FROM FAMILY AND FRIENDS

- Family members and friends who are caring, helpful and accepting will give invaluable support to you and your baby. Others might not know how to respond, so they may not acknowledge the rare condition is there or even dismiss it, perhaps because they feel awkward in not knowing what to say.

It can be difficult when some family members and friends act as if nothing has happened or don't call and visit as often as you expected. If you sense that someone is avoiding you or doesn't know what to say, it can help to make the first move as you will feel more in control of the situation. Try calling or sending an email saying something like, "I hope you're well. We've all been really busy with the arrival of Amy and it would be great to catch up soon so I can tell you about her and find out what's happening with you."

If making the first move doesn't open up the lines of communication, you may feel a whole range of painful emotions. Try giving the person a bit more time and put your energies into family and friends who are supportive.



It is important to note that sometimes you might just not feel like talking about your baby's condition – it's okay to let your family and friends know this. For example you could say, "I am looking forward to seeing you but would rather not talk about it today. What I really want is a good chat and to enjoy your company."

Being gentle and firm about what you want will help your friends and at the same time the support given will be appropriate for you.

## INTRODUCING YOUR BABY TO THEIR RARE CONDITION

- It may seem unnecessary to talk to your baby about their rare condition, but s/he is learning and soaking up all that is

going on around them, even though they cannot communicate through language. Your baby will respond to how you say things and can discern emotions even from very young. Being able to talk confidently and openly about your baby's rare condition will show them you are happy to talk about the way they look and are comfortable with it.

Through daily activities such as playing, looking in the mirror, bath time and bedtime stories, you can talk to your baby in a natural way about their rare condition. For example, let your baby see their own reflection in a mirror and point out their features such as their nose, eyes, the markings and ears. If their rare condition is left out of the conversation, over time s/he will pick this up and wonder why you don't mention it.

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To help them grow up feeling confident about their appearance, introduce a positive name for their rare condition like 'your special mark'.

## TALKING TO YOUR TODDLER ABOUT THEIR RARE CONDITION

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As your child gets older the key to explaining their rare condition is to be open and honest, keeping it simple and using language s/he understands.

- Use words which describe what their rare condition looks like – its shape, size, texture and colour.
- Gradually introduce the medical name in conjunction with these simple explanations. For example, 'You were born with a large mole.' or 'This is your birthmark'.
- At an appropriate age speak about how it affects them. For example, 'Sometimes your birthmark gets very itchy.'

Speaking like this will help your child learn it is okay to talk about their condition and will help them to chat naturally about it to others.

## EXPLAINING TO SIBLINGS

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When a baby is born with rare condition, there are additional unexpected adjustments for siblings to make. They may be understandably jealous of the particular attention the new baby is getting and at the same time perhaps be upset at the way the baby looks.

They are likely to be both curious and concerned so it is wise to help them understand and adjust to their brother or sister's appearance. You can do this by talking to them, giving them simple information about the condition, reassuring them etc. When appropriate provide them with ways to explain their brother or sister's rare condition to others, for example, 'My baby sister has a special mark – it's called a birthmark.'

Set aside time regularly for them to share their feelings and any concerns they may have, especially at times such as when their sibling has hospital appointments or if you both have to stay in hospital etc.

If you take these steps most siblings will adjust well to a having a brother or sister with a visible difference.

## MEDICAL TREATMENT

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In some cases, medical treatment may be recommended soon after birth. It can be distressing to see your baby having medical treatment and understandably, you may feel quite powerless and scared. It's essential to keep reminding yourself that by consenting to the treatment your baby requires you are actually loving, nurturing and protecting him/her.

## GOING OUT IN PUBLIC

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Everyday activities such as going to the shops, the park or taking your baby to playgroup may cause some level of anxiety when anticipating the reactions



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of other people. It is important to remember you will not have a negative experience every time you go out.

Mostly, going out will be uneventful, indeed you may experience kindness from other people. On the rare occasion when comments or difficult exchanges do happen, they may hurt but you can prepare for them and move beyond them. The EXPLAIN–REASSURE–DISTRACT technique is a useful tool when handling other people’s reactions.

## THE EXPLAIN–REASSURE–DISTRACT TECHNIQUE

- This technique can help you to handle other people’s reactions with confidence, allowing you to feel more in control and boosting your self-esteem. It will also help them to move beyond their initial reactions and put them at ease, which in turn makes it easier for you to get on with your normal routine.

### EXPLAIN

- It is helpful to come up with at least one explanation that everyone caring for your child can use about their rare condition. Hearing this consistent explanation helps your child to become familiar and confident about their condition. For example, “That is Danny’s special birthmark. It’s called a ‘...’ and he was born with it.”

### REASSURE

- You may also want to give reassurance about how this affects your child. For example, “That is Danny’s special birthmark he was born with. It’s called ‘...’ and doesn’t hurt him. He loves to play just like you.”

### DISTRACT

- You don’t have to continue talking about your child’s rare condition. Move the conversation on in a natural and appropriate way. For example, at playgroup it is easy to focus on things you may have in common or to engage in small talk.

Using this technique when you notice someone staring at your child or if they ask a question, will diffuse an awkward situation and make everyday encounters more enjoyable for you and your baby.

### COPING WITH UNEXPECTED SOCIAL ENCOUNTERS

- You are standing in the queue to pay at the supermarket when you suddenly notice someone is staring intently at your baby or nudging their companion. You are walking down the supermarket aisle when someone just comes right up and asks about your baby’s appearance. Such casual encounters are often particularly difficult for parents because they are so unexpected. Many parents feel completely unprepared to deal with this sort of curiosity and it can leave them feeling angry, sad or anxious



about going out again. However, such curiosity or concern is a natural human response when we encounter something different or unusual for the first time so be prepared and ready to use the EXPLAIN–REASSURE–DISTRACT technique when this happens:

## EXPLAIN AND REASSURE

- There is no need to provide adults or children you meet in public with indepth medical explanations. A brief and straightforward response will satisfy most people, such as “I see you have noticed my daughter’s birthmark. She was born with it and we like to call it her princess skin”.

When responding in this way, you are also ‘modelling’ to your child how they could respond in the future as they grow up, as they will hear the simple explanations you are giving about their condition.

Sometimes it is enough to just smile and simply say ‘Hello’ to the person as this can break a stare, reassures them and lets people know you are okay.

## DISTRACT

- You don’t have to continue talking about your child’s visible difference once you have given the simple explanation. You can simply move the conversation onto another topic or politely end the

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encounter by saying “It’s been good talking to you to explain my son’s rare condition, but we do have to go now”.

## GOING TO A PLAYGROUP

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Going along to a playgroup is an excellent opportunity for you to meet other parents and children who live locally, on a regular basis. Socialising is particularly important for your baby as they pick up new skills; acquire a better understanding of their environment; learn about themselves and other people. It is through play children learn social rules such as how to make friends, join in and take turns. Through play they also learn and practice new physical skills such as climbing, throwing, drawing etc.

Interacting with others, especially other parents, is also of benefit to you. Although you may have some struggles related to the rare condition, it can make a real difference to feel supported by other parents who are also struggling with sleepless nights, relentless nappy changing and their constant attention being focused on someone else. You will also be able to recharge your batteries while your child is busy playing!

In this type of situation where you may want to make friends with other parents or encourage your child to play alongside other children, it helps to expand your explanations of the rare condition in response to any initial curiosity from them.

## PREPARE YOURSELF

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Preparation is one of the best ways to help you overcome your anxieties and enable you to face situations that may arise.

You could chat to the playgroup leader in advance, explaining your concerns and ask to be introduced to others. You could prepare some small talk to rely on in these situations, such as “Do you live around here? Do you have any other children? How long have you been coming to the group?”

Consider what you hope to gain from this experience and what you could do to achieve it. For example, if you want to help your child to join in, play with him/her alongside other children.

If you really feel uncomfortable, what could you do to look after yourself and your child? At first it could be helpful to go with someone you know – such as your Mum or a friend – who can help you out and give you support when it feels difficult.

## HELPING YOUR CHILD TO JOIN IN

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Young children often need encouragement to join in and play with other children. By modeling for your child the following skills for meeting people, joining in and making friends, your child will feel more confident about trying them out for herself.

- 
- Greeting people by name with eye contact
  - Introducing your child to others
  - Smiling more and making eye contact
  - Asking to join in a game that others are already playing
  - Asking someone else if they would like to join in with what you are doing
  - Suggesting a game or activity
  - Starting a new conversation or changing the subject with a question

These skills will also be helpful for siblings who may find social situations tricky as a result of reactions to their brother or sister's appearance.

## MANAGING RUDENESS

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Some people can be rude, as they have made assumptions or don't know how to respond appropriately to your child's rare condition. Being assertive in how you respond, such as giving the facts without getting angry, can be a very empowering way of dealing with these situations.

For example, you could say "My son's face has a birthmark on it, which is a rare type of birthmark. It was present when he was born."

It is important to teach your child to be confident in managing other people's reactions, but if someone is rude or upsetting, your child needs to know that it is okay to walk away and talk to you or another supportive adult about how they are feeling.

## YOU DON'T HAVE TO EXPLAIN ALL THE TIME

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The suggestions above may feel hard to put into practice, but parents often remark that the more they use the strategies, the more confident they feel. Sometimes just thinking through your options with someone close to you and coming up with some ways to handle situations, can help you to feel more in control and able to enjoy going out with your child.

However, it is not realistic to think you should be able to manage, explain and cope with every situation. Take it one day at a time as some days will be better than other days. On good days you may feel like going to the park or shops and be confident in responding to other people. If you have a day when you have found other people's reactions difficult, be gentle with yourself and do something to help you calm down and relax, such as going for a cup of coffee, inviting a close friend around or just having a cry on someone's shoulder.

## POSITIVE SELF-TALK

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Sometimes you will have to go out, even if it is not a good day. On such days try saying something to yourself that will reassure you and boost your confidence. This might seem strange, but evidence shows the more we think and act positively, the more we are likely to feel positive.



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One of the ways to challenge negative thoughts is through positive self-talk, and the more we do it the more our brains will start to do this on their own. So, the perfectly natural thought of "I can't cope anymore!" is challenged by acknowledging the ways you have coped before and planning how you will cope this time. Below are some examples of positive self-talk:

- "I will be okay."
- "We have done this before and we can do it again today."
- "These are my children and I'm proud of them."
- "I will ignore those who stare. I will smile and show them that I am okay."

## PREPARING FOR NURSERY

Looking is natural when someone new arrives. Getting to know one another and making friends begins with being looked at and looking. We look more and for longer when someone looks different so the other children at your child's new nursery are likely to look carefully, perhaps with surprise and interest. Some may reach out to touch your child's birthmark. Others may ask a question. If these expressions of interest and visual contact are discouraged, your child is at risk of finding it harder in the long run to join in and make friends.

Equipping your child with a simple explanation for the way they look as well as social skills for joining in and making new friends, will stand your child in good stead for starting at nursery.

It is also essential that all staff members are equipped to handle curiosity from other children, parents and visitors to the nursery etc. so that your child can engage in normal social activities without their visible difference becoming the main focus of attention.

Set up a meeting with your child's nursery:

- Before your child starts at the nursery, contact the manager and request a meeting with him/her and the member of staff who will be your child's key worker or teacher.

Share the following information:

- The name of your child's condition and how it affects them
- Any medical needs your child has
- Any special requirements your child has
- Examples of how you explain your child's condition if people are curious or make a comment
- Give the nursery a copy of information material and a link to our website(s).

Helpful questions to ask:

- How do the staff plan to deal with any curiosity about your child's appearance?
- How would they deal with unwanted attention?
- Do they have experience of supporting a child who has a visible difference? How has this child settled in?
- How will the nursery keep you informed about your child's progress?
- Would the nursery consider training to support a child who has a rare condition?

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This meeting needs to take place well in advance so the nursery has time to prepare and provide any relevant training for staff.

## WHAT YOUR CHILD'S NURSERY NEEDS TO DO

- It is vital for all staff members, including administrative and catering staff, to have an understanding about your child's condition and be aware of the social and psychological challenges connected to having a visible difference. They also need to know what to say or do when somebody stares, makes a comment or asks a question about your child's appearance.

Before the term begins, request the nursery shares information with all staff members about your child's rare condition and the support your child requires. This should be done in collaboration with you so that information is shared with your consent.

### **Teach staff the EXPLAIN–REASSURE–DISTRACT technique**

It is important for all staff members to learn the EXPLAIN–REASSURE–DISTRACT technique so they can respond to any curiosity from other children in a natural and straight-forward way.

It is helpful to inform the staff in your child's educational setting what you say by way of explanation so that everyone is using the same simple form of words, both in and out of the nursery or school.

## THINKING ABOUT YOUR CHILD'S FUTURE

- You may already be thinking about whether your child will fit in at school; will they be teased; will their condition affect their physical and mental abilities; will they be loved by others. These anxieties may be influenced by your own personal experience – you may have been teased at school – or by your beliefs – only certain people fit in and get good jobs – or the feelings you are currently experiencing e.g. overwhelmed.

Whatever their origin, these are normal anxieties shared by many parents. If you find yourself overwhelmed by concerns for the future it can help to focus on the present and what support you and your baby requires right now.

Give yourself time – be gentle on yourself; let others help you practically; seek advice and emotional support from friends and people with experience; recognise and acknowledge your abilities and achievements.

As time goes on feelings of sadness/helplessness will lessen and give way to new hopes for your baby. You will be able to move away from focusing constantly on your concerns and start to focus on what is happening for your baby now. You will start to acknowledge and enjoy your child's latest achievement e.g. starting to eat solids; sitting up; crawling; walking etc. and look forward to the future with new hopes and expectations.



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