PARENTS SUPPORT GUIDE

5-11 YEARS

CARING FOR A CHILD WITH A RARE CONDITION

European Reference Network

VASCERN

This guide has been reviewed and validated by the VASCERN Vascular Anomalies (VASCA) Working Group

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Parenting a child with a rare condition throughout their primary years can feel quite overwhelming and stir up a whole range of emotions, such as fear, anxiety and worry. Naturally as a parent, you want your child to reach their full potential and helping them to develop key social and emotional life skills.

This support guide offers strategies and suggestions to help you enhance the social and emotional wellbeing of your child affected by a rare condition, throughout their primary years. These years are often formative for children, the time when they move from being totally dependent on their parents or carers, to more independent individuals who want to find their own way.

THEREFORE WITHIN THIS BOOKLET YOU WILL FIND ADVICE FOR:

- Developing self-esteem in your child
- Helping your child to make friends
- Enhancing your child's school experience
- Talking to your child about their rare condition
- Talking to your child about their feelings
- Talking to others about your child's rare condition
- Supporting siblings
- Parent support

DEVELOPING SELF-ESTEEM IN YOUR CHILD

Self-esteem is about feeling good about yourself, knowing that you are loveable and being proud of your strengths, abilities and achievements. Parents and adults who care for a child play an important part in nurturing positive self-esteem by praising them, acknowledging their unique and loveable qualities and supporting their development of social skills and emotional awareness.

When your child has positive social experiences, they will internalise feelings of self-worth and grow in confidence. Your child will take pride in themselves and what they do; your child will feel good when they do the right thing.

Praise your child

Children flourish when they are praised and when they know that they are loveable and likeable. Be specific in your praise – tell your child exactly what they did that you liked; comment on their strengths, highlight their achievements and positive personality traits.

This will help them understand what it is that you like about them.

EXAMPLES

> “When you told your friend about your birthmark you spoke so clearly. You made it really easy for your friend to understand. I am proud of you for doing that.”

> “I saw you smile and ask that boy to play with you. That was friendly. I see he decided to join you. It looks like you had fun.”

Develop your child’s awareness of self and others

Paying more attention to other people and noticing their individual characteristics can help your child focus on some-thing else if they feel they are being stared at. Encourage your child to notice and describe how other children are behaving by asking your child particular questions like “What can you see?”, “What do the other children like to do?”, “What do you think when you see them playing football?”, “What do you think they think when you play football?”.

Help your child to explore their own strengths and characteristics too. What interests your child? Is there a game they like to play? Is there an activity they like to participate in? What is your child good at – tidying up, reading books, art, sports?

Positive self-talk

Children who have a rare condition may be wary of meeting new children if they have already had unpleasant experiences, but the way we think can also influence the way we feel. Research shows the more positive expectations and thoughts we have, the more we are likely to have positive experiences.

Negative past experiences or fears may lead to a child thinking, “I’m scared” or “They don’t like me”.

Ask your child to focus on positive experiences and try to find positive messages that your child can say to themselves when they are in an unpleasant situation. These selfmottos will challenge the negative thoughts that may pop up when your child meets new people and can boost their self-confidence and self-esteem.

Examples of positive thoughts your child could repeat to themself:

- It is their problem not mine.
- I don’t have to listen. I can walk away.
- My friends like me the way I am.
- I am good at football. I will find someone who wants to play with me.

HELPING YOUR CHILD TO MAKE FRIENDS

Making friends begins with looking and being looked at. Children are likely to look carefully, perhaps with surprise and interest. They may ask a question or look away because they are not sure how to respond. Equipping your child with a simple explanation for their rare condition and teaching him/her how to move the conversation on will get any curiosity out of the way and enable your child to get on with the business of making friends.

Although you may be used to answering questions for your child, or even pre-empting questions by providing an explanation, you will not always be around and so your child needs to learn how to cope with these situations on their own.

Give your child a chance to talk independently

Your child (and siblings) will be watching and learning how you respond to others and answer questions related to their rare condition. Over time your child will become familiar with these simple explanations and when your child is ready, s/he can start to use them for him or herself. You can encourage this by watching closely and giving your child a chance to answer questions or respond to stares or comments.

If another child asks your child “What is that?”, don’t step in with an answer straight away. Keep quiet for a little longer than usual and see if your child gives a response. If not, you could encourage your child to answer by saying to your child, “Do you want to explain?” If s/he doesn’t, you can give a brief explanation and then encourage your child to introduce him/ herself or play a game together – something to move the encounter on to normal social interaction.

Helping your child to find their own explanation

Sit down with your child and discuss the words s/he likes and dislikes. Write down a few possible responses, including an ‘explanation’ statement and a ‘moving the conversation on’ statement and practise saying them out loud. Let your child choose their favourite statements. Your child can then write the statements on a card to keep in their pocket or pinned up on their bedroom wall. Remind your child who s/he can turn to when things don't go so well or if s/he feels low. As your child gets older you can step back, allowing them to respond more independently. This will increase self-confidence and empower your child to embrace their rare condition.

Learning key social skills

If your child can master the following key social skills, s/he will be able to take the initiative when it comes to joining in and making friends at school:

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

Some children will pick up these social skills quite naturally from watching you, whilst other children may need more encouragement and step-by-step guidance, such as the following:

Stage One

Start with the simple skills like smiling and saying hello. Get your child to try smiling and saying hello to people and ask if they notice what the other person does.

Nine times out of ten, s/he will get a smile back and we all know that we are more likely to try things again if we get a positive reaction! The next step is to let your child know that they did a good job and that they should try it on their own next time. It's okay to let your child know that smiling can make both him/her and the other person feel more at ease, and therefore your child will feel in control of the situation.

Stage Two

When your child is relaxed start speaking with them about how they can start to make friends. Ask your child if there is one child at school s/he would like to get to know. What does this child like doing? This is something that your child could use to start talking to the other child about. Your child could ask a question or just comment: "You're really good at drawing" or "You're playing a good game of footie." Other skills include asking if they can join in a game by saying "Good game. You don't mind if I play, do you?"

Your child's teacher could introduce your child to one or two of the social skills listed above and ask him/her how many times s/he can notice the other children doing these things. When your child is ready, the teacher could decide with your child which of the skills s/he wants to try first and set a target for the week ahead, giving your child a safe environment to try out his/her new skills. Your child can then develop these skills in other situations as s/he grows in confidence.

Supporting your child further

- Invite some classmates your child gets along with for a playdate.

- Encourage your child to join a club where s/he can enjoy a hobby or sport of his/her choice, as well as making friends and building confidence, self-esteem and a sense of achievement.
- Take your child to meet other children with their rare condition support events.

TALKING TO YOUR CHILD ABOUT THEIR RARE CONDITION

Your child may be asked “What’s wrong with your skin or leg?” Your child may also turn to you unexpectedly and say, “How come my skin/leg looks different?” Answering questions effectively and learning to talk naturally with your child about their rare condition, will help your child to:

- feel accepted and valued
- increase self-confidence and self-esteem
- answer questions in a straight forward and matter-of-fact way

Sometimes parents decide not to bring up their child’s rare condition due to being concerned they might upset or scare their child. The children we speak to tell us they don’t mind talking about their rare condition – they would rather talk about it than it being ignored.

The following ideas and suggestions can help you develop ways of talking with your child about their rare condition and also ways of explaining their rare condition to siblings, friends and other children.

Why talk to your child about their rare condition?

Children are naturally aware of and curious about differences. This curiosity leads them to ask questions about visible difference, whether it is their rare condition or a visible difference they notice on someone else.

Children’s comments or questions can take you by surprise and are not always polite. However, questions help children to understand themselves and the world they live in. If you can find the words to talk with your child about their rare condition, you can prepare your child to handle other people’s curiosity about their rare condition, with confidence. A child who talks to their parents about their rare condition, will find it easier to answer questions with simple, straightforward answers like: “I was born like this. It doesn’t bother me, or those who know me.”

Building a positive self-image

Your child is likely to encounter reactions of curiosity, surprise or even dislike from others at some point in their life. Talking to your child about their rare condition with confidence and in a matter-of-fact way, instils the belief that s/he can positively embrace their visible difference.

Building positive self-image that includes both the rare condition and an acknowledgement of your child’s talents and positive personality


EXIT FAST

traits, will help your child feel confident in social situations. As a result, negative remarks about your child's rare condition that do not fit with your child's view of themself will be discarded in favour of the storehouse of positive images and beliefs s/he has built up.

Calming your child's fears or concerns about their rare condition
Children will naturally pick up information about their rare condition from what they hear and see around them. Whether it is through attending hospital appointments; treating the rare condition by overhearing conversations about their rare condition, your child is gathering and processing information about their condition. Children think in a different way to adults and if they do not speak about their rare condition with you, your child may begin to over-analyse internally, which can result in unnecessary fear and worry.

Talking to your child about their condition can reduce any fears and will help your child to feel more confident and secure about their rare condition. Good communication also allows your child to feel that s/he can turn to you whenever they want to share their thoughts, feelings and fears.

Preparation for curiosity and questions from others
As your child grows older and becomes more independent s/he will be interacting with new groups of people.

Providing your child with clear and honest information about their rare condition and helping your child to build up a collection of different explanations and strategies for when curiosity arises from other people, will give your child confidence to respond to comments and questions when you are not there.

Furthermore, preparation for curiosity and questions will help your child to accept their rare condition as part of who s/he is and not something to feel embarrassed or ashamed about.

A special note about unkind words
Teasing often focuses on differences and should your child experience unkind words and behaviour from others, it is never easy for the child to cope with or indeed the parents.

Although the ideas in this booklet may help with unkind behaviour, a child should never be expected to cope with this on their own. It is vital that your child knows s/he can get help from his/her parents at home, teachers at school and the responsible adults in other specific settings e.g. clubs etc.

IDEAS AND SUGGESTIONS FOR TALKING TO YOUR CHILD

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Use honest, simple, age-appropriate explanations The key to explaining things to children is to keep it simple; be open and honest; use language your child can understand.

Parents of young children may choose a positive name to describe their child's rare condition to help them feel confident about their visible difference.

Some children have used names such as:

- Chocolate mark
- Angel kiss
- Special mark
- Birthmark
- Brown mark

As your child gets a little older, it is helpful to use words that describe what their condition actually looks like. Think about the colour, shape and texture. It is important for your child to say what key words s/he feels comfortable to use. Sit down with your child and siblings to discuss possible words you could all use to describe the rare condition:

EXAMPLES

> " I was born with a birthmark. Everyone has birthmarks but mine is bigger."
>
> " I was born with a birthmark over my cheek. It's called '…'."
>
> " I put cream on my birthmark because sometimes it is dry and itchy."

Once your child can add a little more information to explain their rare condition, s/he will feel more confident to answer any rare condition related questions before moving onto normal interactions like exchanging names and playing with the other children.

Equip your child to explain how the rare condition affects everyday life

People who meet your child may assume their rare condition negatively impacts everyday life. It is worth discussing with your child how their rare condition might affect them, which in turn will give them a vocabulary to explain it to others.
Here are some explanations about the appearance of the rare condition which you can use to describe how your child's condition does or does not affect them:

EXAMPLE

> " You were born with a large birthmark on your skin. That's all that is different. You enjoy playing and having fun just like any other child."

Using the medical term with your child it is likely your child will have heard the medical terminology in conversations you've had with doctors; nurses; friends and family members and so your child may be wondering what the term means. You can explain what the term means to your child, so they become confident with using the medical name when explaining the rare condition to others as they get older.

How parents communicate is important

A lot of meaning is portrayed in our body language and tone of voice. It is important for you to practise saying things with confidence, making eye contact and in a relaxed manner. We all pick up on body language and if it does not match the content of what is being said, we tend to believe the non-verbal cues. If you can talk with your child about their visible difference in a confident and matter of fact way, s/he will have a positive example to follow.

Talk about similarities and strengths

The tips so far have focused on explaining a rare condition. There is so much more to your child than just the rare condition which makes them both unique and loveable as well as similar to others. It is important to comment on what your child has in common with others, particularly as this becomes increasingly important for children as they head towards adolescence and wanting to fit in.

When your child chats about their friends, comment on their similarities such as, what they enjoy doing together. When your child remarks that s/he dislikes maths and loves sports, respond by pointing out others they know who are like that, for example, "I was like that when I was your age. In fact, I still don't like maths even though I try my best to help you with your homework."

Take time to praise your child when s/he does something well

Children thrive on positive comments as it helps them build a sense of who they are, what they can do and to feel good about themselves. Children with a self-image that is multi-faceted are less upset when a negative comment is made about one aspect of who they are. In their mind, they know they are worthwhile.

EXAMPLE

> You walk into your child's room and find him/her brushing their hair in front of the mirror. You can take the lead by standing next to her and saying something like, "I really like my bright blue eyes and my smile but some days I don't like the shape of my nose. What about you, what things do you like about yourself? What don't you like so much?" You could also comment on the things you like about your child, the things s/he enjoys and the things s/he does that makes you, and others, smile.

Finding time to talk

As your child grows older, his/her level of understanding will increase, and s/he is likely to want to know more. You may need to sit down for short periods of time to talk. Choose a time when your child is in a receptive mood. If you can, prepare by thinking ahead about what you would like to say and what your child might ask.

Even though your child might be interested to find out more about their rare condition, older children might be nervous to talk about it directly, so it can be a good idea to find a 'safer' environment where they won't think or feel all the attention is directly focused on them. For example, on a car-ride; preparing a meal; looking at photos; having a bath; or whilst waiting for a sibling to finish an after-school club etc.

If you want to open up the conversation, you could start by saying "I've been wondering what you say to the kids at school if they notice your birthmark? Maybe we could think of some things to say together?"

Someone else for your child to talk to
It is natural, as children reach secondary school, for them to begin to want greater independence and so they are likely to share less with their parents. Encourage your child to talk to someone supportive and suitable with whom s/he can share feelings, experiences and any concerns. This could be a family friend; a counsellor at school, or patient (organisation) advocate.

TALKING TO YOUR CHILD ABOUT THEIR FEELINGS

A natural instinct for some parents is to protect their child by avoiding certain situations which they think might upset them, for example, going to public places where people may stare or comment.

No matter how much you may want to protect your child from people's reactions to his/her rare condition, your child will encounter them at some point. Experiencing a variety of negative feelings such as anger, sadness and irritation is part of life and so children need to learn how to name these feelings; talk about them; respond to them and express them appropriately.

Start by commenting on how your child's mood seems to you. It is helpful to link their behaviour, body language and facial expressions because this helps children to learn how they express their emotions and to identify them.

EXAMPLES

- " You have a big smile on your face and your eyes are shining. You seem really happy today."
- " You were silent and didn't want to talk. That normally happens when something has upset you. I am happy to listen if you want to talk about it."

By offering words to describe your child's feelings, you are providing an opportunity for them to discuss their feelings with you in an open way.

Helping your child to express their feelings
It is important to give your child the opportunity to express how they feel about their appearance. If your child says, "I hate my rare condition", let him/her know it is natural to feel the way they do, as we can all have certain aspects of ourselves that we do not like. Just by your child expressing how they feel, will bring a sense and measure of relief. Also, being able to say, "I hate my rare condition" allows your child to identify specifically what s/he doesn't like about themselves, rather than it being unspoken and it could develop more generally into "I hate myself because I am different."

Firstly, ask your child what it is s/he doesn't like about their rare condition.

The answer to the 'what' question may be a very practical reason such as itchiness, which can be alleviated quite quickly by applying cream. If your child struggles to answer the 'what' question, you could then ask your child the 'why' question – why don't they like their rare condition. The answer to the 'why' question may highlight the psychosocial impact of having a visible difference.

Parents' Feelings

Many parents feel angry; guilt; sad or exhausted from having to deal with other people's reactions and responses.

There may be times when you want to protect your child by keeping your emotions to yourself by hiding them, especially if someone makes an unkind comment in the course of your daily activities. However, children pick up and are aware of emotions through body language and facial expressions, even though they may be unable to articulate verbally emotions they see in others.

In such situations, it will help your child if you acknowledge your feelings simply and model how to deal with the situation. For example, if a reaction makes you feel upset, you could say to your child "When I feel like this, I like to have a chat with a friend. If you want to chat about it, or if you just want a hug, let me know."

What if I don't get it right?

If you're finding yourself stuck for words, try writing down how you would explain the rare condition to your child and to other people. Read over what you have written so you begin to memorise your words. You can always edit what you write, as you think through your explanations in more detail and consider what your child or other people may ask in response to what you have written.

If you have talked with your child about their rare condition and on reflection feel you didn't answer questions the way you would have liked, it's not too late to go back and try again. You are teaching your child valuable skills throughout this process.

Remember you don't need to have all the answers. As your child gets older, s/he may have questions that you can't answer. Encourage your child to write their questions down and take them to their next doctor's appointment.

TALKING TO OTHERS ABOUT YOUR CHILD'S RARE CONDITION

It is normal for people – children and adults – to notice differences so going anywhere in public means people are likely to notice your child's visible difference.

Young children are incredibly curious. They look intently at your child's rare condition and ask very straightforward questions. Adults might stare at your child or do a double take. They may forget to say "Hello" and instead blurt out something inappropriate, such as "What happened to your child?" Parents often feel completely unprepared to deal with this sort of curiosity, which may create feelings of sadness, anger and anxiety.

The EXPLAIN–REASSURE–DISTRACT technique enables you to:

- Make the first move
- Act in a way that makes you feel more in control
- Resolve any curiosity
- Maintain your child's self-esteem and self-confidence
- Model for your child how to respond to such curiosity so that they can increase their own skills in meeting new people.

THE EXPLAIN–REASSURE–DISTRACT TECHNIQUE

The general rule of thumb is, the more the interaction means to you, the more you expand the technique.

Scenario 1

If you are aware of adults or children noticing your child's rare condition whilst you are at the supermarket check-out, walking down the street or waiting at the bus stop, there is no need to give an in-depth, lengthy explanation.

Try smiling or simply saying "Hello" to reassure people or to break a stare. Some people will then ask questions, so a brief and straightforward answer will satisfy most people, allowing you and your child to get on with the day.

Scenario 2

When you want to make friends with other parents at the school gate or help your child to meet others at an after-school club, it may mean you both want to explain your child's rare condition in more detail.

A little more information about your child's rare condition, lets people know your child is just like any other child.

EXAMPLES

" It's just a birthmark."
" Tom was born with a large birthmark."
" I have a large birthmark. It is brown, lumpy and hairy but it doesn't hurt."

Scenario 3

Other children's comments or reactions can feel particularly difficult to handle, especially if they ask awkward questions or come straight up and touch your child's birthmark. Your child will be interacting with children on a daily basis at school so the way you respond to other children, will help your child to learn how to deal with and manage the reactions of their peers. Following an explanation, its good to distract by talking about something other than your child's appearance.

EXAMPLES

" This is Matthew. He has a special mark but you can't catch it. What is your name?"

> “ It’s just a brown mark by her eye. It doesn’t hurt. Do you want to go on the swings together?”

Scenario 4

There will be times when you don’t feel up to responding to others. Try just using the ‘Distract’ part of the technique by asking them a question about themselves or moving the conversation on.

EXAMPLE

> “ I don’t feel like talking about it right now. I’ll tell you about it another time. Did you go anywhere nice at the weekend?”

Scenario 5

Bear in mind, there may be other thoughts people have about your child’s rare condition, such as
“Is the birthmark contagious?”
“Does your child need extra help?“
”Does your child have developmental delays?”

Although some children with a rare condition may need extra help, this is not always the case. By expanding the EXPLAIN–REASSURE–DISTRACT technique, you can reassure people and clear up any misconceptions.

EXAMPLE

> “ Daniel was born with a large birthmark. It’s not contagious and he can still do everything other children can do.”

Managing rude comments

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 by how you respond, such as giving the facts without getting angry or abusive can be a very empowering way of dealing with this. For example, “My son’s face has a birthmark on it, which is a type of birthmark that he was born with.”

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, their teacher, or a supportive adult about how they are feeling.

YOU DON’T HAVE TO EXPLAIN ALL THE TIME

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

Look after yourself

You are not expected to find a way to manage every situation. Take it one step at a time. 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, you may like to do something to calm down or relax, such as go for a cup of coffee with a close friend or just have a cry on a loved one's shoulder.

Positive self-talk

Sometimes you will have to go out, even if it's not a good day. If you don't want to explain or you need a confidence boost, try having something to say to yourself that will reassure you. This might seem strange, but evidence shows that the more we think and act positively, the more we are likely to feel positive.

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 that you have coped before and planning how you will cope next time.

EXAMPLES

" 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.

SUPPORTING SIBLINGS

When a child has a rare condition, it affects everyone in the family to some degree. Most siblings cope well when they are supported to understand their brother or sister's visible difference and they have had the time to share their feeling and concerns.

However, siblings will be aware of unwanted stares and comments, they may be asked questions about their brother or sister's appearance, so it is important for siblings to be included in discussions about responding to others so they too can feel confident when faced with questions or comments. Here are two examples of how siblings can respond:

EXAMPLES

> " This is my sister. She's got a birthmark. Do you want to play with us?"
>
> " This my younger brother. He has a birthmark. Do you have a brother too?"

ENHANCING YOUR CHILD'S SCHOOL EXPERIENCE

Children spend a large part of their lives at school. During primary years, maximising your child's opportunities for positive social interactions can influence their feelings of self-worth, ability to build friendships and to do well at school.

When your child receives their school place, request a meeting with the head teacher and class teacher to share the following information:

- The name of your child's condition and how it affects them
- Any medical needs of your child
- Any special requirements your child may have
- Examples of how you explain your child's condition to other children
- Provide the school with the a copy of information material and a link to our website(s).

It helps to ask the following questions:

- How do the teachers plan to deal with any curiosity about your child's appearance?
- How do 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 school keep you informed about your child's progress?
- Would the school consider training to support a child who has a rare condition.

What your child's school 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.

Before the term begins, request that the school shares information with all staff members about your child's condition and the support your child may require. This shouldbe done in collaboration with you so that information is shared with your consent.

Teach staff the EXPLAIN–REASSURE–DISTRACT technique

It is important all staff members are taught the EXPLAIN–REASSURE–DISTRACT technique so they can respond to any curiosity from other children in a natural and straightforward way. It is helpful if you can prepare a list of things you say so that everyone is using the same simple form of words both in and out of school.

For example: "Jess has a mark on her face. We call it a birthmark. It's like a mole only bigger. Have you got any moles too?"

SUPPORT FOR PARENTS

As a parent of a child with a rare condition, there can be moments when you feel overwhelmed. Many parents find it helpful and reassuring to talk to someone who understands to a degree, what they are going through. It can be liberating to be able to express your feelings openly about having a child with a rare condition.

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