PARENTS SUPPORT GUIDE

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12-17 YEARS

CARING FOR A CHILD WITH A RARE CONDITION

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

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Adolescence is a time of moving from the immaturity of childhood into the maturity of adulthood. There is no single event or boundary line that signifies the end of childhood or the beginning of adolescence. The passage from childhood into and through adolescence is composed of a set of transitions that unfold gradually and that touch upon many aspects of a young person's behaviour, development and relationships.

This guide focuses on practical strategies for parents to support their child living with a rare condition throughout their teenage years.

UNDERSTANDING ADOLESCENCE

Adolescence coincides with a psychological breakthrough in a young person's life. The thoughts, ideas and concepts your child develops during this period will greatly influence their future life and play a major role in character and personality formation. It is also a time of rapid physical development, deep emotional changes and notable mood swings. These developments and changes are exciting but can also be equally confusing and uncomfortable for your child and for you as their parent.

Adolescence is one of the most, if not the most significant transition in a person's life when the notion of identity becomes of the utmost importance, and it can be bewildering. For young people this is a time of often perplexing questions, such as "Who am I?", "What do I want to be?" and "How do I get there?"

It is also a time when a young person may begin to challenge, doubt and enquire about everything that touches their lives. This may be seen occasionally as defiance, and can be particularly exasperating for parents, who may feel their adolescent child questions everything just for the sake of argument.

As they become more independent, young people want to try out new things, but often have little experience to fall back on when things get difficult. At the same time, young people are increasingly aware of how others, especially their peers, see them and they may desperately try to fit in with the world. This may produce rapid changes in self-confidence and behaviour – feeling very adult one minute, very young and inexperienced the next.

As a parent, you need to be quite flexible in your parenting style throughout these years, and at times you may feel overwhelmed, so try to remember that parenting a teenager is a season and it will eventually pass!

Young people want recognition of who they are, even if they have no clear idea of what that might be yet. With your support, tolerance and understanding, their growing need for identity and independence can be achieved.

APPEARANCE AND IDENTITY

Adolescence is often a time when appearance and identity can suddenly become intertwined. Body image and the way they see themselves is a major concern for girls and boys in this age group. Concerns about physical appearance contributes more than any other factor to the overall level of self-esteem in young people.

Some teenagers struggle with their self-esteem when they begin puberty because their bodies go through many changes. These changes, combined with a natural desire to feel accepted, leads many young people to compare themselves to the people around them or to the ‘perfect’, airbrushed images of actors and celebrities which they are bombarded with on social media, in the press, on TV and film.

The adolescent world that they are now trying hard to fit into may seem to your child to value the appearance rather than the substance of individuals. For young people living with a rare condition these concerns may be amplified by long held beliefs and doubts about their body image.

Most children have a ‘body awareness’ even from an early age, but this usually involves comparisons of growth and maturity. There is also an awareness of physical difference with others. Despite living with a rare condition since birth, this increasing awareness of ‘difference’ can have a powerful effect on your teenager’s self-confidence.

Encourage your child to be open about his feelings If your child is concerned about their appearance, encourage them to speak about their feelingsand worries. Create a ‘safe place’ for your child to openly express their doubts, anger and frustrations. Ensure your child knows you are listening and acknowledging all the issues they are trying to cope with. By not minimising or dismissing your child’s anxieties you will also be acknowledging your recognition of their growing maturity.

Offer reassurance

The need to conform to the ‘norm’ or to be the same as their peers can at times be overwhelming to a young person. Physical changes to the body can sometimes seem to happen rather quickly and your child may need a lot of reassurance, especially if s/he is not growing or maturing as quickly as their friends.

Reassure your child by explaining that it’s normal to be a little concerned or self-conscious.

Remind your child that all their peers will also have anxieties and doubts about their own appearance. Let your child know everybody is different. There are early bloomers, late developers, and slow but steady growers. In other words, there’s a wide range of what’s considered normal.

Be positive about your child’s appearance

Self-belief and self-value are important factors in overcoming feelings of negativity. Negative statements from your child such as: “I am so ugly!” or “I hate the way I look” can be addressed positively and sensitively by complimenting your child about various aspects of their appearance as often as you can: “You have the nicest eyes”; “You have a great smile”; “You have really lovely hair”; “You look really fantastic in that outfit.”

Try to avoid making well-meaning statements such as: “Don’t worry, it’s the inside that counts.” Many young people living with a rare condition find these comments discounting of their appearance. Your child will want to know you find both their inner qualities and outer appearance attractive.

It is also important to help your child focus on aspects of their appearance that make them feel confident. Young people may focus only on what they find negative about their appearance, so to help your child feel more confident, encourage them to buy a new piece of clothing, or to try a new hairstyle.

Help your child to challenge their beliefs about appearance

Films, TV programmes, magazines and social media often suggest we must look a certain way in order to be happy and successful. You can help your child to challenge this belief by asking them why s/he wants to look like a particular person, for example, a Hollywood star. You will find that often this 'beautiful' person represents a particular dream or a lifestyle that your child believes is unattainable. Your child may say something along the lines of "Because I want to be in films." Find out more by asking, "Are you interested in acting?" If s/he says "Yes", you could say something like, "Let's not wait for Hollywood. Let's look at how you can fulfil your ambition. Would you like to find out about acting classes?" In this way, your child can begin to understand that dreams can sometimes be achieved by 'going and getting' rather than 'waiting and hoping'.

Encourage activities and interests

Young people with a rare condition may have feelings of doubt associated with finding a place for themselves in the world. Their goals may be tempered with thoughts of "I can't join in that" or "I don't think I can learn to do that."

Challenge these negative thoughts or beliefs and support your child's talents, hopes and desires by encouraging them to participate in activities and things that interest them. A positive image of self that includes not only their appearance and rare condition but also an acknowledgement of all their talents and positive personality traits, will help your child to feel more self-confident and improve her/his self-esteem. Remember to remind your child of everything s/he is good at ... dancing ... singing ... cooking ... sport ... impressions etc.

HELPING YOUR CHILD TO GAIN INDEPENDENCE

The primary goal of the teen years is usually to achieve independence. For this to occur, teenagers will start pulling away from their parents. You may find that your sweet and loving child who had previously wanted to please you will suddenly begin asserting himself/herself and strongly rebelling against parental control.

You may also find that you have become increasingly embarrassing to your teenage child. Your views, appearance and values may now be scrutinised and often rejected as old-fashioned, out of date and far too conventional.

These rejections and conflicts are usually not to do with your personalities, but simply arise from the fact that you are 'the parents' from whom your children must become independent if

they are to have their own life. However, it is understandable to feel rejected during this time, so it may help to think back to your own adolescent years. Can you remember your struggles with how you looked, how you felt, how you related to your parents and the world in general? Are you ready for those changes in your own son or daughter? Are you willing for their opinions and tastes to differ from your own? Parents who are aware of what's coming usually cope better with it.

Setting Boundaries

Parents and teenagers often complain about each other's behaviour. Parents often feel they have lost any sort of control or influence over their child. Teenagers need their parents to be clear and consistent about rules and boundaries, but at the same time may resent any restrictions on their growing freedom and ability to decide for themselves.

Teenagers will often appear unhappy with the expectations their parents place on them. However, they need to know and usually understand that you care enough about them to expect things from them. Appropriate grades, behaviour and adherence to the rules of the house are important standards to maintain. If you have appropriate and achievable expectations, your child will usually try to meet them.

Involve your teenage children in making family rules – like all of us, they are more likely to stick to rules if they can see some logic to them and have helped to make them. Parents should pick their battles – not all frustrations are worth an argument. It's usually better to spend time praising good decisions and behaviour. It is an interesting fact that most annoying habits will usually burn themselves out once parents stop reacting to them.

Letting go

Every parent needs to acknowledge and be prepared to allow their now grown up child to become independent and self-sufficient. Letting go can be particularly hard to do if your child has a rare condition, as their basic need for independence may often be affected by their own feelings of self-doubt and uncertainties such as:

- Will I be able to live my own life?
- Will I be able to be who I want to be?
- Will I be able to make my own decisions?

The fine balance needed between being encouraging and realistic about their present capabilities is not always easy.

Sometimes what is needed most is a continual presence of encouragement, reassurance and understanding. The temptation to be overprotective is understandable but helping your child to manage independently long-term is the best kind of support and guidance you can give.

TALKING WITH YOUR TEENAGE CHILD ABOUT CMN

Young people can often have very real worries, anxieties and fears about their rare condition. If their condition is not spoken about directly, they may begin to wonder why. Sometimes, young people end up feeling very alone and scared to talk about it, or they may even think that they have a visible difference because they have done something wrong.

If you talk to your teenage child about their rare condition with confidence and in a matter-of-fact way, you can allay such fears before they arise and this in turn will help them to feel more confident and secure.

You will also be providing your child with words that s/he can use to formulate sentences in order to respond to other people's curiosity as well as to express their own feelings, thoughts and fears about their rare condition.

Most importantly, you are instilling the belief that their difference is okay. A positive image of self that includes not only their rare condition but also an acknowledgement of their attractiveness, talents and positive personality traits will help your teenage child to feel confident – particularly in social situations.

Your child has been living with their rare condition from birth so you may already have established ways of talking about it. The following tips may help you both find ways of talking about their condition:

- Utilise the websites of patient organisations to help your teenage child understand more about their rare condition.
- Describe how your child's condition does or doesn't affect them.
- Use the medical name of the rare condition.
- Talk about similarities your child has to other people as well as their differences.

MANAGING OTHER PEOPLE'S REACTIONS

Meeting people in a social setting can be unnerving for many teenagers, but for young people with a rare condition it can be especially intimidating. A young person with a visible difference is likely to encounter curiosity in the form of staring or double-takes and sometimes even expressions of shock. It is important to teach your child how to manage other people's reactions in a positive way and to develop a confident manner, especially as your teenage child will be doing more and more things independently from you. Being prepared with responses to comments, questions and staring is an important way of helping them to feel in control.

Equip your teenage child to know what to say

Make sure your child has clear and honest information about their condition. This will enable them to develop sentences to use when people ask about their condition, for example "I was born with a birthmark. It's no big deal, it doesn't hurt". Encourage your teenage child to practise what s/he wants to say and how to say it with you at home first until s/he feels comfortable talking about their rare condition in other situations or other contexts.

When your child feels more comfortable, s/he can even take the initiative rather than waiting for other people to say something, for example "I see you've noticed my hands. It's a large mole I was born with. They don't hurt at all".

Remember to praise your child and show your recognition of their growing maturity by saying, "I really loved the way you handled that, well done!"

Role modelling

As a parent, how you handle and manage other people's reactions, as well as both what you say and the manner in which you say it, will provide an important example to your child. By looking relaxed, confident and at ease you are providing your child with a fundamental model that will help them in their own social interactions.

Reassure

Try to reassure your child that one of the main reasons people will look at them is to communicate with them. We all look at people's faces both when we are speaking and when we are listening. It is a normal and natural part of communication.

Unfortunately, if your teenage child is self-conscious about their appearance this apparent examination by others can be uncomfortable and may be thought of as intrusive. It is important to explain that people are naturally curious and that we all tend to seek out and want to know more about anything that is new to us. Everyone instinctively stares at faces because faces provide information; they tell us the mood and often the unspoken thoughts of the other person.

Handling rudeness

Some people can come across as rude if they don't know how to respond appropriately to a difference in appearance. Show your child how to be assertive. Being able to state what they feel and want without getting angry or abusive can be a very empowering way for your child to deal with rudeness. For example, your child could say: "I have …. It's a rare type of birthmark which I was born with. I'm happy to talk about it with you, rather than you just looking at it."

Remind your child that it is also okay to walk away and, if in school, to find a teacher for some reassurance and support.

You don't have to explain all the time

There will be times when your teenage child does not feel up to responding to others. Let your child know it is okay not to explain all the time. During these times, it may help your child to focus on positive self-talk that they can say to themselves to challenge the negative thoughts that may pop up when s/he meets new people.

A little further on in this guide you will find a list of positive self-mottos which many young people with a rare condition have found helpful.

THE EXPLAIN–REASSURE–DISTRACT TECHNIQUE

The early years Parent Support Guides explain a technique to help you as a parent to communicate with other people about your child's rare condition. Now your child has reached their teenage years, you may want to explain the technique to your teenage child for him/her to use themselves.

The EXPLAIN–REASSURE–DISTRACT technique enables your teenage child 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 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 other people noticing your rare condition whilst you are walking down the street or waiting at the bus stop for example, 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 to get on with the day.

Scenario 2

When you want to make friends with new people you meet, you may want to explain your rare condition in more detail than a passing comment. A little more information reassures people, letting them know the facts about your rare condition, such as the name of your birthmark and that you were born with it. Then you can distract the person you are talking to, by focusing on what makes you just like them, e.g. your hobbies, the latest news, everyday life conversation.

Scenario 3

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.

Scenario 4

Bear in mind, there may be other thoughts people have about your rare condition, such as is the rare condition contagious? Do you need extra help? Although some children with a rare condition may need extra help, it is not always the case, so by expanding the EXPLAIN–REASSURE–DISTRACT technique, you can reassure people and clear up any misconceptions. You could talk about your experiences of living with your rare condition, including positive experiences.

THE IMPORTANCE OF FRIENDS

Although close relationships with friends exist well before teenage years, during these years the relationships change in significance and structure. There is a sense of real camaraderie, a total understanding of one another's feelings, hopes and fears. For the first time there is also a feeling of it is 'us against them' and an acknowledgement of the divide between the generations. At this point, your child may consider their friends to be more important and influential than their family.

These relationships are important as they are part of learning how to get on with other people and gaining a sense of identity that is distinct from that of the family. However, fears of being in the 'right' group as opposed to the 'wrong' group can bring new pressures when wanting to belong and be accepted seems to be so important.

Young people with a rare condition may have lots in common with their peers but they can also often feel left out and unsure of themselves, particularly if attention is focussed only on aesthetics and outward appearances.

It is important to encourage your teenage child to engage in community, to make new friends with shared interests. Support your child in broadening their social activities by investigating various clubs, such as youth groups, football clubs and dance classes. In your home have 'open door policy' to friends.

Home needs to represent safety, love and affection to your child, but it must not become a haven against the world. Rather, the world should be ever-present and welcomed in.

BOYFRIENDS AND GIRLFRIENDS

The confusing state of adolescence is further complicated by the arrival of increasing emotional feelings towards their peers. Boys/girls who had been judged for years as nuisances by your child can suddenly become of interest with an emotional attachment. "No one is ever going to love me" is now added to the list of worries.

The way teenagers feel about themselves is often determined by how people respond to them, for example if they respond with love, they feel lovable. If the response is one of exclusion, they will feel unlovable.

Your teenager's sense of self-worth becomes ever more determined by the opinions of others.

For young people with a rare condition there is often an added worry and a yearning to look the same as their peers. Statements such as "She is beautiful, that's why she's got a boyfriend, it's never going to happen to me" or "He is tall and good-looking that's why he has a girlfriend, it's never going to happen to me" can be very difficult for parentsto hear.

During this time, your teenage child wil be ever more intently aware of the attitude you as a parent are taking so it is important that you continually re-affirm an optimistic message by being positive, hopeful and constructive.

Remind your teenage child that other people's reactions to us are greatly influenced by how we present ourselves. Appearing to be friendly, approachable and interesting are key elements in the success of any new relationships.

Young people who have a rare condition often have a huge anxiety about what will happen when they do find a boy/girlfriend. They may worry about how to talk about their condition.

If you think your teenage child may be worried about these issues, ask your child sensitively if s/he would like to talk about their concerns. Reassure your child there are always solutions and it may just take a bit of practice or trial and error to find what works best for them.

POSITIVE SELF TALK

Give your teenage child and yourself a confidence boost by having reassuring self-talk mottos to say to yourselves when you are finding a situation difficult. The acronym SMILE is a wonderful resource to display in your home, with positive moto's to memorise:

- Stand out from the crowd
- Make the most of your uniqueness
- Inspire others
- Love the skin you are in
- Embrace your visible difference

SIBLINGS

When your 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 feelings and concerns.

However, siblings will be aware of unwanted stares and comments. They may be asked questions about their brother's 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.

Sibling rivalry can be a common factor in the family home. As a parent it is wise to be aware that sibling rivalry can be triggered by the considerable amount of time you may need to spend caring for your child with the rare condition. From medical appointments to ensuring their emotional wellbeing, parents can find their them-selves consumed by caring for their child with the rare condition. Ensure you set aside one-to-one time with siblings, giving them your full attention and focusing on their needs.

Now support events. It is important that siblings have a safe place to meet other siblings of children living with a rare condition, to share experiences and develop friendships.

STARTING SECONDARY SCHOOL

When your child receives their secondary school place, you may want to request a meeting with the headteacher and year group leader to share information about the rare condition and how it affects your child. You can provide the school with a copy of information material and a link to our website(s).

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