



PARENT GUIDE

Caring for a child with Congenital Melanocytic Naevus



12-17
YEARS

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 CMN 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 CMN 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 CMN 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 feelings and 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 they are 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 CMN 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 they want 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 they say "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 CMN 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 CMN 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 they are 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 themselves 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 CMN, 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 CMN. 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 CMN 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 they 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 CMN.

Most importantly, you are instilling the belief that their difference is okay. A positive image of self that includes not only their CMN 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 CMN 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 Caring Matters Now website to help your teenage child understand more about CMN.
- Describe how your child's condition does or doesn't affect them.
- Use the medical name Congenital Melanocytic Naevus (CMN).
- 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 CMN 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 they want to say and how to say it with you at home first until they feel comfortable talking about their CMN in other situations or other contexts.

When your child feels more comfortable, they 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 CMN. 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 they meet new people. A little further on in this guide you will find a list of positive self-mottos which many young people with CMN 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 CMN. 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 your teenager is aware of other people noticing their CMN whilst they are walking down the street or waiting at the bus stop for example, there is no need for them to give an in-depth, lengthy explanation. Instead, they could 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 them to get on with the day.
- Scenario 2** When your teenager wants to make friends with new people they meet, they may want to explain their CMN in more detail than a passing comment. A little more information reassures people, letting them know the facts about CMN. Your teenager might include the name of their birthmark and that they were born with it. Then they can **distract**, by focusing on what they have in common, e.g. your hobbies, the latest news, everyday life conversation.
- Scenario 3** There will be times when your teenager doesn't feel up to responding to others. Try just using the **distract** part of the technique by asking the other person a question about themselves or moving the conversation on.
- Scenario 4** Bear in mind, there may be other thoughts people have about CMN, such as is the CMN contagious? Do people with CMN need extra help? Although some people with CMN may need extra help, it is not always the case, so by expanding the **EXPLAIN-REASSURE-DISTRACT** technique, your teenager can reassure people and clear up any misconceptions. Your teenager may choose to share their experiences of living with CMN, 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 CMN 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 CMN 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 parents to hear.

During this time, your teenage child will 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 CMN 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 they 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 Caring Matters acronym poster **SMILE** is a wonderful resource to display in your home, with positive mottos to memorise:

- S**tand out from the crowd
- M**ake the most of your uniqueness
- I**nspire others
- L**ove the skin you are in
- E**mbrace your visible difference

The poster can be ordered directly from the Caring Matters Now website or by emailing info@caringmattersnow.co.uk

CMN AWARENESS CARD



Our CMN Awareness Cards are available to purchase on our website. The idea behind this card came from one of our Online Baby and Toddler Events following a discussion around raising awareness and navigating conversations with members of the public. These handy, pocket-sized cards direct recipients to a webpage specially focused on engaging with visible difference, supporting our members in educating the public about CMN in a subtle yet powerful way!

SIBLINGS

When your child has CMN, 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 CMN. From medical appointments to ensuring their emotional wellbeing, parents can find themselves consumed by caring for their child with CMN. Ensure you set aside one-to-one time with siblings, giving them your full attention and focusing on their needs.

Siblings are always welcomed at Caring Matters Now support events. It is important that siblings have a safe place to meet other siblings of children living with CMN, 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 CMN and how it affects your child. You can provide the school with our school transition letter, Caring Matters Now School Support Guide and CMN Medical Booklet which can be downloaded from our website. To request a copy of the school transition letter or to receive hard copies of our resources please email info@caringmattersnow.co.uk.

You may also want to signpost the school to the 'HOW DO YOU **CME NOW?**' schools resource pack. The resource pack has been produced by Caring Matters Now as a PSHE teaching resource focused on challenging negative perceptions of visible differences.



FINDING FURTHER SUPPORT FOR YOUR TEENAGE CHILD

Young Ambassadors Programme

The Caring Matters Now **Young Ambassadors Programme** aims to provide young people living with CMN (12 to 24 years) a platform to develop the following key skills:

- Communication
- Building Relationships
- Teamwork
- Leadership
- Public Speaking
- Media Engagement
- Innovation



YOUNG AMBASSADOR

The Young Ambassadors Programme is composed of two levels. Level 1 invites our Young Ambassadors to complete one task per year in Secondary School, including the opportunity

to represent Caring Matters Now at Regional Gatherings and to take on a fundraising challenge. Level 2 extends beyond Secondary School into the early years of further education and working life. Registering for level two gives our Young Ambassadors the opportunity to complete the prestigious Dale Carnegie Course. The course is designed to equip you with the communication and human relation skills required to be successful in any setting. This world famous programme of self-development helps the leaders of tomorrow leverage their skills so they can strengthen relationships between colleagues, solve problems, create collaborative cultures, boost morale and motivation within teams, and ultimately deliver outstanding results in any area of concentration. Having this experience on their CV is sure to set our Young Ambassadors apart!

Further details about the Young Ambassadors Programme can be found on the Caring Matters Now website or by emailing support@caringmattersnow.co.uk

Teens and Young Adults Support Contacts

Caring Matters Now has a Teens Support Contact (12-16s) and a Young Adults Support Contact (17-24s) available to chat with teenage members and young adult members, to share experiences and answer any questions about living with CMN. The support contacts know first-hand the difficulties attached to living with CMN, especially throughout the teenage years and into early adulthood. More details are found on the Caring Matters Now website under the **Support tab > Teens Support**.

Young adult members are invited to register as an adult member whenever they turn 18, rather than continuing under a parent's registration. Adult members have access to our Adult Contact Team, are invited to our adult events and to participate in adult-focused research studies. Our Young Adult Support Contact assists our members in this transition and ensures that they have all the information they need to get involved! Adults experiencing new problems with their CMN can be referred to the Adult Clinic in St Thomas' Hospital London.

Teens Events


Caring Matters Now hosts events throughout the year for our teenage members which are carefully planned with the input of our teenage members. All details can be found on the Caring Matters Now website or by emailing support@caringmattersnow.co.uk

Teens Support Resource




In partnership with the Centre for Appearance Research, the CMN Young Ambassadors have created an interactive information and support resource specifically for young people. The resource covers some of the key issues for young people with CMN, including feeling more confident, coping with anxiety, starting a new school or college, dealing with social situations, and using social media. The resource includes information, personal stories, tips from some of the Young Ambassadors, and a toolbox of psychological techniques that young people can use themselves. The CMN Teen Support Toolbox is available on the Caring Matters Now website and was funded by the Vocational Training Charitable Trust Foundation.



Caring Matters Now

 Support Helpline: 0300 373 3422

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