



SCHOOL SUPPORT GUIDE

**Caring for a child with Congenital Melanocytic Naevus
in an educational setting**



SCHOOLS



Why have I been given this guide?

You have been given this guide because you are or will be supporting a child or young person with Congenital Melanocytic Naevus, more commonly known as CMN, in your educational setting.

Children living with CMN often have associated psychosocial challenges such as: anxiety, poor self-esteem, lack of confidence and low mood. Dealing with other people staring, asking unsolicited questions or making comments about the CMN can have a negative impact on the psychosocial development of a child. Children living with CMN may also be undergoing treatment and require practical support and additional educational support.

This school support guide has been produced to provide nursery staff, primary school staff and secondary school staff:

- information about Congenital Melanocytic Naevus (CMN)
- how to support a child living with CMN in the educational setting
- how to manage curiosity in the educational setting
- access to teaching resources focused on accepting appearance diversity

Where can I get more information?

Caring Matters Now is the leading UK charity supporting children and adults living with CMN. Please see the website for more information about CMN and further support.

www.caringmattersnow.co.uk



WHAT IS CONGENITAL MELANOCYTIC NAEVUS (CMN)?

Congenital: present at birth

Melanocytic: melanocytes are cells in skin and hair that produce the pigment melanin. The cells in a CMN look most like melanocytes and they produce pigment, so they are called melanocytic.

Naevus: birthmark (the plural is naevi).

Single small CMN are found in 1% of all new-born babies. However, large or numerous CMN are rare, occurring in around 1 in 20,000 births.

Site: CMN can be on any part of the skin, including palms, soles and scalp, and sometimes inside the mouth.

Colour: The colour is usually some sort of shade of brown to black but sometimes they can be more reddish. The colour is often very mixed inside the CMN with smaller areas of different colour on a background colour. CMN at birth are often black or even dark purple/red.

Hairiness: CMN usually have hair growing out of them, although this is often not visible at birth and can remain unnoticeable throughout life. The hair colour can be darker than the child's head hair, or the same, or very occasionally lighter. If a CMN is on the scalp there is usually more luxuriant hair growth over the naevus and the hair grows faster than on the rest of the scalp. Occasionally, CMN are completely hairless, even ones that occur on the scalp, or they can have patchy hair loss or hairs without pigment (like grey hair).

Texture: The texture of large CMN tends to be different from that of normal skin, being softer, looser and more wrinkled. The CMN can be nearly flat or can be very folded or lumpy.

Fragility: Many CMN are more fragile than normal skin and can therefore tear more easily if they are knocked or scraped. However, they do not bleed any more than normal skin and they tend to heal well with minimal scarring.

Dryness: Some CMN are drier than the surrounding skin so they need to be washed without soap and moisturised regularly. Occasionally, CMN are very itchy which can be due to dryness or eczema in the CMN, or sometimes for no apparent reason. This itchiness can usually be treated using creams and ointments.

Size and Growth of CMN: CMN can cover up to 80% of the body and almost always grows in proportion to the child. In other words, CMN will usually continue to cover the same area of skin as at birth. Smaller CMN sometimes appear as the child grows and can look like lots of smaller moles.

What causes CMN?

CMN are caused by a change in a gene which happens to the baby while it is developing in the womb. A change in a gene is called a mutation. A mutation means that there has been a 'spelling mistake' in the gene, and a gene is just one of the instructions in our body. Mutations happen all the time when babies are being formed, and during our lifetimes, but many of them are completely unimportant. If, however, a mutation happens in an important gene, then it can have a big effect. The most common gene to cause CMN is called NRAS, which is the cause in about 70% of cases of CMN. NRAS is a very important gene and the mutation in CMN is a very important place in NRAS. The only other gene currently known to cause CMN is called BRAF, which is the cause in about 6% of cases. In the other cases the gene is still not known. It seems to make no difference whether the mutation occurs in NRAS or BRAF – the problems for the patient are the same. The mutation that causes CMN happens entirely randomly and is not caused by anything the mother or father have done before or during pregnancy.



Neurological complications

Problems in the brain or spinal cord are the most common complication seen in children with CMN. The most common problem is pigment-containing cells (like a CMN) in the substance of the brain. Other rarer problems include benign brain or spinal tumours, too much fluid in the brain, or abnormal brain structure. All of these neurological problems are more common with larger and more numerous CMN. The current recommendations are that any child born with two or more CMN should have a routine MRI scan of the brain and spine, preferably by the age of 6 months.

The overall chance of finding an abnormality on an MRI scan in children with multiple CMN (two or more at birth) is around 20%, but only around half of these children will have any actual problems. If they do have problems these can be fits (convulsions), developmental delay, or problems with their limbs.

Melanoma

Melanoma is a cancer of melanocytes, the skin cells which produce pigment and which make up CMN. It used to be thought that melanoma was very common in people with CMN, but we now know that overall it is rare, occurring in around 1-2% of all people with CMN over their lifetime. However, the risk is higher in people with brain or spine disease found on an MRI scan

after birth (in these cases around 10%), and there is a peak of risk during childhood. When considering these risks, you need to bear in mind that every one of us has a risk of about 50% of developing some kind of malignant tumour at some time in our lives, and in the UK we estimate the risk of melanoma in the normal population to be about 0.5%.

CMN Medical Booklet

To receive a FREE copy of the CMN medical booklet for your school, please email info@caringsmattersnow.co.uk

PREPARING FOR SCHOOL

To ensure a smooth transition into an educational setting (nursery, primary and secondary) for the child living with CMN, we recommend two preparation measures to be implemented:

- Staff to prepare for reactions of staring, curiosity, and concern from children
- Staff to be equipped in supporting the child living with CMN in the educational setting

Allow plenty of time to implement both preparation measures. For example, once the school receives confirmation that the child with CMN has secured a place for the following school year, start your preparations by giving this booklet to each staff member. Invite the parents into school to meet staff members and to explain more about the condition and ways to support the child.



WORKING WITH THE PARENTS

It is important to ask the parents how they and their child cope when encountering new people. Key questions to ask include:

- Do you have strategies for coping with reactions?
- What do you say if someone makes a comment or asks a question?
- What sort of words do you use to describe the CMN?
- What can we do to support your child as they transition into their new school?

Explain to the parents that you are planning to teach their child to respond with confidence when children in the new school setting are curious about CMN.

It is important to ask the parents what practical support the child may need in school. For example, applying sun cream throughout the day. Children with CMN can and should enjoy a normal life. They should be protected from the sun in the same way we would recommend for all children regardless of whether they have CMN on not. It is important that they do not get sunburnt.

WORKING WITH THE CHILD

A child living with CMN will transition well into the educational setting if they have:

- at least one strategy for dealing with curiosity in a positive way
- a basic understanding of why people are curious about CMN.

MANAGING CURIOSITY & MODELLING EFFECTIVE RESPONSES

A very young child may appear to be unaware of their CMN.

However, sooner or later, the child living with CMN will encounter other children in their educational setting who will notice the CMN and become curious. Children will often be outspoken with their curiosity and ask direct questions such as, 'What's that on your face?'

Children may reach out to touch the child's CMN, and even try to rub off the CMN.

If children are encouraged not to stare at the CMN, they will then often avoid staring by turning away from the child. As a result, the child with CMN will find it harder to play socially and make friends.

How staff within the educational setting react to the curiosity from children is crucial in diffusing any negative emotions regarding the visible difference. Furthermore, positive reactions from adults will enable the child with CMN to feel more confident to embrace their visible difference, to talk openly about their CMN and to love the skin they are in.

Children learn much from watching and experiencing what other people do. As influential adults, you and your colleagues will help a child who has CMN simply by responding effectively to expressions of curiosity and concern about a child's visible difference. This will teach the child with CMN to respond positively to other people's reactions in everyday life.

When responding to children who are naturally inquisitive and ask questions or make a comment about CMN:

- Consider if the child living with CMN is in earshot and respectfully respond to these questions and not shy away from them.
- Chastising children for asking genuine questions or comments is unhelpful and can lead to further stigma and judgement towards CMN.
- Don't judge someone beyond the facts. For example, don't say, 'Jodi has a birthmark, it must be awful for her.'
- Emphasise kindness and acceptance.
- Use matter-of-fact language when appropriate. See the EXPLAIN-REASSURE-DISTRACT technique below.



USE THE EXPLAIN-REASSURE-DISTRACT TECHNIQUE

EXPLAIN

It is helpful to come up with at least one explanation that everyone caring for the child can use about their CMN. Hearing this consistent explanation helps the child to become familiar and confident about their condition. For example, *'That is Danny's special mole. It's called a CMN and he was born with it.'*

The exact form of words that everyone will use needs to be discussed with the child's parents. Find out if the child already uses a specific form of words to describe their CMN, for example, *'It's my birthmark.'* If not, you will need to discuss with the parents, words and phrases that they feel comfortable with. This calls for sensitivity and respect. Parents' cultural background may also have a bearing on what they want to say.

It can be helpful to draw up a list of all the words and phrases you and the child's parents think would be most helpful to say. Depending on the age of the child, it may be helpful to ask the child with CMN what they would like you to say in response to the curiosity.

At first, it is best if everyone uses the same simple form of words, both in and out of school. Over time, a more extensive range of responses will develop depending on the social situation.

REASSURE

It is important to give reassurance in your response to the child asking the question. For example, *'That is Danny's special mole he was born with. It's called a CMN and doesn't hurt him. He loves to play just like you.'*

As part of the reassurance, you can show an interest in the child who asked the question or showed the initial curiosity. For example, *'That is Danny's special mole he was born with. It's called a CMN and doesn't hurt him. He loves to play just like you. Do you have any moles?'*

DISTRACT

This is a key social skill to model as part of the technique. When you model it, you will be helping the child to manage the level of attention given to their CMN.

You can move the conversation on in a natural and appropriate way. For example, in the classroom it is easy to turn the focus back onto the lesson being taught.

Using the **EXPLAIN-REASSURE-DISTRACT** technique will diffuse what could be an awkward situation for the child with CMN and make everyday encounters a more enjoyable experience.

SUPPORTING SIBLINGS

A child with a brother or sister with CMN may also get comments and questions about their sibling's appearance. They can also learn to deal with curiosity, concern and comments by using the techniques of prepared responses described above.



SELF-HELP RESOURCE FOR OLDER CHILDREN AND TEENAGERS LIVING WITH CMN



Caring Matters Now, in partnership with the Centre for Appearance Research, has produced a self-help toolkit of simple and effective psychoeducational activities.

The activities can be worked through at home or at school with older children and teenagers living with CMN.

The resource aims to provide self-help support for young people aged 12-17 with CMN. These self-help techniques are designed to improve confidence, self-esteem, tackle anxious feelings and equip young people with the skills they need to feel comfortable in their own skin. The toolkit is accessible free of charge on the Caring Matters Now website:



www.caringmattersnow.co.uk/support/teens-support/online-teens-support-resource/

TEACHING RESOURCE

It is crucial that schools support all of their pupils to understand appearance diversity; it is an important element of Ofsted's Behaviour and Attitudes judgement which explores how schools recognise and act to address specific needs and to ensure pupils actively support the well-being of other pupils.

Caring Matters Now has produced a teaching resource for primary and secondary schools to promote appearance diversity. The resource includes lesson plans, a beautifully presented photographic book featuring children and adults living with CMN, personal story video clips and a poster to display in the classroom or around school promoting appearance diversity acceptance.

To order the teaching resource for your school, please email info@caringmattersnow.co.uk



WHY CONSIDER APPEARANCE DIVERSITY IN TEACHING?

Research shows children as young as 4 years can have negative attitudes towards others because of how they look (Parnell, Williamson, Lewis & Slater, 2021). This is important as appearance-based stigma can negatively impact children's overall self-esteem and quality of life. Young children's worlds are small, and therefore it is important to acknowledge and include all types of diverse appearances within teaching to tackle this issue at an early age

STAND OUT PRINCIPLES

A school's culture has a significant impact on a child's educational experience. You can help to foster a positive, inclusive culture at school by adopting the following **Stand Out** principles:

- S**pread the word about visible difference equality at school
- T**hink positively about visible differences - don't let negative assumptions get in the way
- A**pproachable - display a warm manner when meeting someone with a visible difference
- N**ormal, natural eye contact - look, but don't stare
- D**eal with discrimination - if you see it, report it
- O**wn up to not knowing about visible differences: find out more
- U**nderstanding - show understanding for the challenges people face
- T**ry again - don't give up if people doubt your belief in visible difference equality

DO'S AND DON'TS IN THE CLASSROOM

Do respond to all appearance-based bullying the same

As not all diverse appearance characteristics fall under the Equality Act, your school may not have the same procedures in place to tackle appearance-based bullying regarding weight in the same way it does with race, for example. Nonetheless all bullying based on appearance can be harmful for children's body image. All appearance-based bullying needs to be taken seriously with the same procedures followed, irrespective of the reason for the bullying.

How? Ensure your school has a no tolerance approach towards all appearance-based bullying.

Don't speak negatively about your own and others' bodies

It is important that you model to children how to be kind and non-judgemental towards your own and others' bodies. Do not berate your own body in front of children. This can be difficult if you struggle with your own body image but speaking kindly towards your body can have a positive impact on you and is actively role modelling good body image for the children.

How? Be aware of your own body image and beliefs, making sure to reflect on your own feelings and how these may impact the children.



Do weave in diverse appearances through representation

Consider subtly representing other appearances in the images you use whilst teaching. It doesn't necessarily just have to be a stand-alone topic to be discussed, it could be woven through different elements of the curriculum. Sometimes addressing the specific issue, or the specific problem, can draw more attention to it and make it stand out more. A good place to start could be as simple as showing different people. Representing different appearances in books and videos can help increase exposure. This is important if you have a range of diverse appearances in your class, but also extremely important if you do not. If children aren't naturally exposed to diverse appearances in their school, in their community, where they live, then later in life they may be less accepting or have less understanding or be more ignorant about differences.



How? Include books, toys and displays which represent more diverse appearances.

When using images, videos and resources in class, actively look for ones which represent a range of different appearances.

Don't avoid the topic of diversity

We have found that many teachers feel that this topic is tricky and are unsure how to navigate it. Teachers are 'worried about saying something wrong' but also 'don't want to seem naïve that we don't know enough.' This can lead to teachers feeling they want to tackle it, but also, as some have told us, that 'it's easier to just avoid it because then you don't upset or offend'. Avoiding acknowledging or discussing diversity can lead to further taboo and stigma towards certain appearances. Therefore, it is important school staff have honest and open conversations about how they would like to include diversity of appearances. These conversations need to be held in a safe space and allow school staff a chance to express fears and ideas for this topic.

How? Set up a support group with other staff to have these discussions. Use this guide as a starting tool.





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