

# Living with congenital melanocytic naevi

Helen Stroud

**C**ongenital melanocytic naevi (CMN) are brown or black birthmarks which can come in a variety of shapes and sizes. It is a rare condition, affecting one in 20,000 babies, which often goes undiagnosed due to a lack of awareness. Most people with CMN are born with the condition, while around 1% of CMN appear after birth, usually in the first year of life. They can be very large, measuring 50cm or more, or small and numerous, sometimes referred to as satellite naevi, covering up to 80% of the body. The condition has many expressions, some of which can lead to medical complexities. CMN can also grow internally, which in the worst cases can be fatal.

I was born with CMN, but I didn't receive a diagnosis until adulthood. Different doctors classified my birthmarks with various terms, but it took years until I found out what they were. I felt alone for so many years, always wondering why I had these strange birthmarks and nobody else did.

My CMN comes in the form of a large, dark brown birthmark, covering my entire back, alongside hundreds of smaller brown spots across my arms, legs and face that range in size from a small freckle to a 1p coin. Due to the coverage of my CMN, it has been impossible to hide

completely, which as a child and teenager I found very hard to deal with. However, as an adult I have altered my mindset about having the condition and have learnt to embrace it.

I am keen to raise awareness of CMN with medical professionals working in dermatology or with young babies, so that children born with CMN can be diagnosed early and families can receive support to navigate the condition.

## Early life

My story begins with the doctors and midwives who delivered me having no idea why my skin was different. They had never seen anything like this before, and initially they thought it was just bad bruising. However, as the birthmarks became darker, my parents became more

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concerned. Back in 1988, there was no option to do a quick Google search to find a diagnosis. We attended a few naevus support groups, but they were not very accessible to us in Liverpool at the time, and consequently we didn't really connect with other families who had children with CMN. What lay ahead were many years of appointments, questions, and uncertainty. We had very little information about the condition and just had to get on with it.

At just a few days old, I was lucky enough to be introduced to an incredible Consultant Plastic Surgeon in Alder Hey Children's Hospital, Liverpool. Dr Jones (not his real name) was willing to do something that other doctors at the time were too nervous to attempt; he performed dermabrasion on my back, across a series of operations, when I was just a couple of weeks old. My mum has spoken about the mixed emotions of both fear and relief as Dr Jones held me in his arms as a newborn and said he could help. He reassured her that he would do whatever it took to find a team who could support him with the operation, despite the challenges it presented.

I can't remember this of course, but my parents have talked to me about it a lot and have shown me photos of the before and after results. Unfortunately, it was not possible to remove the birthmark on my back completely, as it was too large and deep into the skin. However, the procedure did succeed in making the birthmark significantly lighter.

As a toddler, I continued to visit Alder Hey Hospital, where Dr Jones performed further operations to remove some of the satellite birthmarks on my arms and legs. He also removed a large amount of excess tissue that I had in my right leg, which was also linked to my CMN. I ended up with a scar that goes diagonally across the front of my right calf, but at least I could finally fit my wellies on!

Being in hospital for these operations as a toddler is probably one of my earliest childhood memories. With little support from friends or family, my sister (who was three years old at the time) would have to come to the hospital with mum all day, as my dad still had to work. The hospital staff at Alder Hey were so kind to me on the ward, bringing toys to my bed when I couldn't get out to play. They were also super friendly with my sister, so she didn't feel left out. I don't ever remember feeling scared before the general anaesthetic; the staff always put me at ease, although I am sure it was a much more worrying experience for my parents.

### Growing up with CMN

Growing up with a rare skin condition, I was very self-conscious about the way I looked, especially as a teenager. I struggled with mean comments about my birthmarks; other children (or sometimes adults) called me 'spotty' or said it looked like I had mud on my legs. This hugely dented my confidence, but I tried hard not to let it show. I didn't always tell my parents as I didn't want to upset them.

I learnt to wear clothes that would cover up my back and legs as much as possible. I was grateful that I had a group

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of close friends at school, and even though they didn't understand my condition, they didn't ask questions and accepted me for me.

I found it particularly hard during the summer. Back in the 90s, it was harder to get suitable swimwear to cover my birthmarks, and people were not as conscious about protecting their skin from sun damage as we are today! I often noticed people staring when I went swimming on holiday, while others made blunt comments about my skin's appearance. When my great aunt, who lived in Australia, sent over two swimsuits that had a high back, it enabled me to cover up and have more confidence to go in the water. I always had to be lathered from head to toe in a high factor sunscreen (which I still do today!). However, I now understand that children with CMN can and should enjoy a normal life. They should be protected from the sun in the same way that all children should, regardless of whether they have CMN or not.

### Adult life

When I started university, I was excited for a new adventure, but I was also concerned about people judging me again for my appearance. I made friends, but I was very guarded about being intimate with anyone, nervous that they would laugh or be disgusted by my birthmarks that I usually kept hidden.

However, it was at university that I met my soulmate, Johnny. He never once questioned my condition and now, years later, we are married with two children, neither with any signs of CMN.

Becoming a mum has really helped me to be more accepting of my skin, and I want my boys to grow up with a positive outlook on visible difference. It is a good thing that we are not all the same, and I wish I could go back and tell my younger self to be more confident and love the skin you're in.

As an adult, I have been fortunate to meet two incredible consultants who have helped me to reduce the pigmentation of the birthmarks on my legs and back through laser treatment. While this initially had an impressive impact, over the years, the pigmentation in my birthmarks has become darker again. I have also experimented with different camouflage make-up, but now, I have decided to accept my skin for how it looks.

### Caring Matters Now

I first discovered the charity Caring Matters Now back in 2020. I will never forget that day. We were in the middle of the first lockdown, and I was getting breakfast ready for my son, who was two at the time. We had the radio on in the kitchen and they started talking about this charity called Caring Matters Now. I was only half listening, but as they described the work of the charity, I quickly realised it supported people just like me. I immediately looked up the charity's website and burst into tears.



### CMN, MRI scans and melanoma

To some degree, the size and number of CMN matters. A smaller CMN has less chance of developing melanoma than a larger one. The chance of developing melanoma in a single CMN is very low. However, we have found that size and number is not as important as an MRI scan result.

Research has found that children born with CMN should have an MRI in the first year of life. The most common finding on an MRI scan is something called intraparenchymal melanosis. This is where little groups of melanin containing cells – a bit like little naevi – are seen inside the brain itself. This is unlikely to increase your chance of melanoma.

What seems to be more of an issue is whenever you have problems along the coating of the spine or brain, or if there are many different structural problems in the brain. If your MRI scan is normal, your chance of developing melanoma seems to be lower (1-2%) than in people who have abnormalities seen on the brain MRI (10-15%). However, this won't be the same for everybody, as it depends uniquely on what is found on your MRI scan. It is not clear why this is the case; one of the most obvious reasons is that a lot of the melanoma that develops in childhood starts in the brain or spinal cord. Research has not yet found if this is true into adulthood, as we only have data from a childhood cohort, up to the age of about 18 years old. However, the vast majority of cases will not get melanoma.

At last, at the age of 32, I had finally discovered that there were other people with my condition. As my research into the charity continued, I was overwhelmed when I saw photographs from the How Do You C Me Now exhibition that took place in London in 2019. The collection of photography demonstrated the diversity of the CMN condition across children and adults, both male and female. It was uplifting to see other people with CMN, and I found it inspiring that they had been so brave to take part in the exhibition to help raise awareness of the condition and the charity.

Research funded by Caring Matters Now has helped me to understand more about my condition. For example, I now know that CMN are permanent and grow in proportion through childhood, so continue to cover the same area of skin as a child grows. I have also learnt that CMN is caused by a genetic mutation in the womb, most often, the gene NRAS, or more rarely, the gene BRAF. Most CMN birthmarks are a dark, chocolate-brown colour, but they range in colour from light brown to black. Depending on the gene responsible, they may darken, become thicker, develop nodules, or grow hair,

others may be wrinkled, fragile and soft. I have learned that there is no way to prenatally determine or prevent CMN from occurring,

I now understand that CMN can have a profound impact on both physical and mental wellbeing. And while CMN has presented challenges to my self-esteem, I am very fortunate that I have not experienced any further medical complications resulting from CMN.

### Research into CMN

UK research into CMN takes place at Great Ormond Street Hospital NHS Foundation Trust (GOSH), and the Francis Crick Institute in London. The research team is led by Professor Veronica Kinsler who works in each institution and is also affiliated to the UCL GOS Institute of Child Health.

CMN has been described over many centuries and is likely to have existed for near enough as long as humans have been around. As with many other conditions, however, it is only recently that we have been able to start to understand what causes CMN and why it appears in particular people.

*This information has been provided by Caring Matters Now who work in close partnership with Professor Kinsler, Great Ormond Street London. Recent Research Publications can be accessed via the Caring Matters Now website.*

*Please note that due to the continuing advancement in CMN research, it is important to seek current guidance and advice by contacting Caring Matters Now.*

### About Caring Matters Now

Caring Matters Now was founded in 1997 by 17-year-old Jodi Whitehouse, who had extensive CMN covering her body. It is the only UK charity supporting those affected by congenital melanocytic naevi.

### The charity's vision

CMN has a vision of a world where no one suffers from CMN.

It focuses its work in three areas:

- SUPPORTING those affected by CMN. The Support Pathway can be viewed via this QR code:



- Funding pioneering RESEARCH to find a cure for CMN
- Raising national and international AWARENESS of CMN.

For more information and support, please visit [www.caringmattersnow.co.uk](http://www.caringmattersnow.co.uk) or use this QR code:



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