



Caring Matters Now

Adult
Support Structure

Caring Matters Now – Adult Community

Caring Matters Now is committed to supporting all those affected by Congenital Melanocytic Naevi. This document has been put together to give an overview of the adult support Caring Matters Now offers to our 18+ members.

The history of Caring Matters Now

Caring Matters Now charity was initially set up in 1997 by Jodi Whitehouse, a 17-year-old patient at Great Ormond Street Hospital with extensive Congenital Melanocytic Naevi. Dr Atherton, who was at that time the CMN specialist at Great Ormond Street Hospital, introduced his CMN patients to Jodi and her parents. Jodi's family provided support to those similarly affected by the condition. This was the first known and only dedicated support group in the UK. It was clear that those affected by CMN and their families were in desperate need of accurate information, advice and contact with others affected by the same condition.

In the early years of the charity, the majority of our members were children because all our contacts came through Great Ormond Street Hospital. However, we did have one adult member from Scotland and this member was an integral part in the development of Caring Matters Now. The aim of Caring Matters Now was, and continues to be, to support those affected by CMN, so therefore, all our support days have been developed over the years to best support the members who were reaching out for help.

In much more recent years, slowly but surely, we have had adults starting to attend our support days and becoming members of the charity. The support days very much cater for all ages. However, at first glance it may seem that the support days are aimed at children, as we have lots of activities for young ages. The activities are in place to free up parents to talk to other adults. Dr Kinsler also attends all support days, and is always keen to talk with adults as well as children.

In 2013 the CMN trustees decided that it was now time to expand the adult support as our adult membership had grown. During that year, we developed an adult online community forum, which we encourage the CMN adult members to join. This is a safe arena to share experiences and support one another.

In 2014 the CMN trustees decided to hold the first ever CMN adult gathering in London, as the charity now had a sufficient number of adult members to hold such an event. The event proved to be a great opportunity to bring

together our adult members and listen to what support they would like to see in place. Rather than dictating the support we offer, we want to very much gain an understanding as to how adults would like to see the support develop. Dr Kinsler, Jodi Whitehouse and Val Unsworth also attended the event. Dr Kinsler was able to give correct medical advice to the adults who attended and she also gave a small presentation on her CMN research work, which encouraged our adult members greatly.

Following the adult gathering, the CMN trustees sent out an online survey to all our adult members, asking for their feedback on how the charity should progress in adult support. From the results of this survey and listening to our adult members at the adult gathering in 2014, Caring Matters Now has been able to produce this document, outlining the support structure we believe is needed for adults affected by CMN.

Message from Jodi Whitehouse – Adult support contact

As an adult with CMN, I am sure you can understand that my main goal is to offer the best support we can to all ages. For many years, myself and one other lady were the only adult members of Caring Matters Now. It has taken time for our adult membership to grow in number and I am so pleased that we are now at a stage in offering substantial adult support.

If you have any questions or suggestions regarding adult support, please do contact me at jodi@caringmattersnow.co.uk

Jodi Whitehouse - Adult Support Contact

Caring Matters Now Adult Support Structure

As a result of the feedback we received as to how Caring Matters Now can better support our adult members, below are the areas in which we as a charity are going to develop our adult support structure:

- Arenas for meeting others affected by CMN
- Opportunities to receive medical advice directly from Dr Kinsler
- To receive CMN research updates
- Support on how to handle every day issues relating to CMN

Arenas for meeting others affected by CMN

This aim will be achieved in the following ways:

- ✓ Adult Gathering: One organised events each year whereby CMN adult members have the opportunity to meet one another, exchange experiences and develop friendships.
- ✓ Online community: Establish a well organised and easily accessible online forum through the Caring Matters Now website where adult members can be in contact with one another.
- ✓ Social media forum: Establish a private Facebook group for CMN adults only. Facebook is now used in everyday life, therefore chatting to fellow adults with CMN, will become a natural part of life.
- ✓ Support Days: All adults are welcome to attend the support days Caring Matters Now holds each year. The days cater for all ages. At first glance it may seem that the support days are aimed at children, as we have lots of activities for young ages. The activities are in place to free up parents to talk other adults. Therefore, the charity encourages our adult members to attend these days.

Opportunities to ask questions & receive information directly from Dr Kinsler

This aim will be achieved in the following ways:

- ✓ Adult Gathering: Dr Kinsler will attend the one organised adult event each year. At the adult gathering, Dr Kinsler is able to answer questions about CMN.
- ✓ Support Days: Dr Kinsler attends all CMN support days. This is an opportunity for adult members to attend and speak directly to Dr Kinsler about any concerns they may have.
- ✓ CMN medical booklet: The CMN medical booklet, written by Dr Kinsler is available to all members. The booklet gives the most up-to-date medical advice.
- ✓ Urgent advice: Dr Kinsler is available on v.kinsler@ucl.ac.uk for any

general questions about CMN. Unfortunately she is unable to see adult patients on a professional basis, so urgent medical enquiries should go via GP or local dermatologist, which whom Dr Kinsler is happy to liaise if needed.

To receive CMN research updates

This aim will be achieved in the following ways:

- ✓ Adult Gathering: Dr Kinsler will attend the one organised adult event each year. At the adult gathering Dr Kinsler will give an update on her latest research findings and will answer any relevant questions regarding her research.
- ✓ CMN newsletter: Research updates are included in every CMN newsletter. The newsletters are posted to all members twice a year and available to download online.
- ✓ CMN website: Research updates are available to read on the Caring Matters Now website.

Support on how to handle every day issues relating to CMN

This aim will be achieved in the following ways:

- ✓ Support Literature: Caring Matters Now works in partnership with Changing Faces, who produce excellent support literature specifically for adults with visible differences. The support literature is available to download directly through Changing Faces website. There is also a link on the Caring Matters Now website.
- ✓ Learning from one-another: Through meeting other adults with CMN, members will be able to support one-another by sharing experiences and coping strategies. This is often a very helpful way in learning new coping strategies for every day issues relating to CMN.
- ✓ Psychologist: Attendance of a psychologist at a CMN organised support day to give advice and presentation on coping strategies.