



**Caring
Matters
Now**

ADULT SUPPORT STRUCTURE POLICY

Policy Owner: Jodi Whitehouse
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CARING MATTERS NOW
PO BOX 184
ST IVES
PE27 9DU

Email: info@caringmattersnow.co.uk
Website: www.caringmattersnow.co.uk

**Caring Matters Now
Adult Support Structure Policy**

Our Mission

Caring Matters Now is the only dedicated UK charity to provide information and support for those affected by Congenital Melanocytic Naevus. The charity has three main aims:

To support those affected by CMN
To raise awareness about CMN
To raise funds for the CMN research

Contact Information

Board of Trustees

Mrs Valerie Unsworth (Chair)
Ian Chance (Treasurer)
Anne McIntyre
Robert Jackson
Bronagh Cleland
Ruth Gold

Staff

Jodi Whitehouse (Chief Executive Officer)
Lucy Hardwidge (Support & Communications Officer)
Lisa Sly (Finance & Office Administrator)

UK Registered Charity No:

1120988

Postal Address

Caring Matters Now, PO Box 184, St Ives, PE27 9DU

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.

Adult Support Development - Background

Caring Matters Now 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 members were children because all referrals 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. Our support has developed year on year, as our membership has continued to grow.

In more recent years, we have had adults affected by CMN starting to attend our support events and becoming members of the charity. The support events cater for all ages. However, at first glance it may look like our support events 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. Prof. Kinsler and the CMN research team attend various support events and are always keen to talk with adult members.

In 2013 the Caring Matters Now Board of Trustees decided to expand our adult support strategy as our adult membership had grown. The charity developed an online community forum for adult members, which enabled adult members to engage with one another more regularly to share experiences and offer mutual support.

In 2014 the Board of Trustees hosted the charity's first dedicated adult support gathering in London. The event proved to be a great opportunity to bring together adult members and listen to what support they would like to receive. Prof. Kinsler, Jodi Whitehouse and Val Unsworth attended the event. Dr Kinsler answered CMN related medical questions and presented her CMN research work to the group, which encouraged our adult members greatly.

In response to the feedback received from our adult members, Caring Matters Now recruited a voluntary adult support contact in 2015. The adult support contact joined the wider support contact team to offer a listening ear, host adult support gatherings, answer any questions regarding living with CMN and signpost adult members to relevant charity support materials, research updates and charity events. Since this appointment, the adult support structure has continued to develop year-on-year, engaging many of our adult members.

Caring Matters Now Adult Support Structure

Caring Matters Now is committed to supporting all those affected by Congenital Melanocytic Naevi. In recent years, Caring Matters Now has been expanded our dedicated support for adults affected by CMN. Below are the areas in which we as a charity aims to support our adult membership:

- Arenas for meeting others affected by CMN
- Opportunities to receive excellent CMN medical advice
- To receive CMN research updates
- Support relating to every day CMN concerns

Arenas for meeting others affected by CMN

This aim will be achieved in the following ways:

- ✓ **Adult Gathering:** Host a yearly gathering for adult members to meet one another, exchange experiences and develop friendships.
- ✓ **Social media forum:** Manage a private Facebook group for CMN adults only.
- ✓ **Regional Gatherings:** All adult members are welcome to attend regional gatherings hosted by Caring Matters Now. The events cater for all ages. At first glance it may appear the regional gatherings are aimed at children; however, the regional gatherings are organised to engage children which in return, frees up parents to talk other adults.
- ✓ **Annual Conference:** The Annual Conference is a 2-day event. The programme includes adult-focused activities, workshops, CMN research presentations, plus plenty of free time for adults to chat, share experiences and develop friendships.

Opportunities to receive excellent CMN medical advice

This aim will be achieved in the following ways:

- ✓ **CMN Annual Conference:** Professor Veronica Kinsler attends the annual conference, along with her research team. This is a fantastic opportunity for adult members to speak directly with Prof. Kinsler about any CMN-related concerns they may have.
- ✓ **CMN Adults Clinician List:** Adult members will be able to access details of doctors across the UK who have an understanding of CMN. The clinicians list has been developed by adult members sharing details of their own doctors, and therefore already having some medical knowledge of CMN.
- ✓ **CMN medical booklet:** The CMN medical booklet, written by Professor Veronica Kinsler is available to all members. The booklet gives the most up-to-date medical advice and can be distributed to medical clinicians.

To receive CMN research updates

This aim will be achieved in the following ways:

- ✓ **Adult Gathering:** Professor Veronica Kinsler will provide a written update on her latest CMN research findings.
- ✓ **INSPIRE Magazine:** An annual research review is included in the INSPIRE magazine published by the charity. The magazine is posted to all members and available to download online.
- ✓ **CMN website:** Research updates are available to read on the Caring Matters Now website,

along with medical publications.

- ✓ **Annual Conference:** Professor Veronica Kinsler and the research team present their most recent findings at the annual conference. Following the presentations, attendees are invited to ask questions in relation to the CMN research.

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.
- ✓ **Adult support team:** The adult support team consists of 4 adults affected by CMN. The adult support team are available to listen to our adult members, chat, share experiences and answer any questions you may have regarding living with CMN. You can contact the adult support team by emailing adult@caringmattersnow.co.uk.
- ✓ **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 support:** A team of research psychologists from CAR (Collective Appearance Research) attend the annual conference. The team offer psychosocial workshops to all attendees and are able to offer advice on coping strategies.