

Hello,

Thank you for asking to join our group.

- If you are considering joining the group as a supporter of a family member or friend with Carney Complex (CNC) we would ask you to go to our website instead:  
<https://www.carney-complex.org/support-a-person-with-cnc/>  
Thank you for your understanding.
- If you or your child, spouse, partner or someone you are a carer for has been diagnosed with Carney Complex or it's a possibility that you/ they may have it, then you are welcome to join our group.
- If there is someone pivotal to your care and support who doesn't fit the above criteria then please contact the Admin Team.

Before we can add you, we kindly ask you to take a few minutes to read through our membership guidelines and group rules.

Thank you  
Jennifer, Francesca and Angela

## About our Group

The Carney Complex Community Support Group encourages its members to ask questions and share in a way that helps and supports others.

We encourage sharing of stories, offering suggestions and ideas, in a manner that is appropriate - based on understanding, kindness and empathy.

## Guidelines

### 1) Introduction

We welcome and introduce every new member to our group and would like to encourage you to share your story and tell us a bit about yourself so we can get to know you and your journey (eg. Which Country you live in?; Is English your First language?; What has been your experience?; etc.).

### 2) International group

As this is an international group, we would like to make you aware that our members have different cultural backgrounds, ethical, religious and political views and different health systems. Although posts are in English, for a good percentage of our members English is not their native language.

- a) **When writing posts** please be mindful to share from your own perspective. We all experience CNC differently. In both scientific and medical literature the terminology mild/ severe is not used - think of it more as different levels of (genetic) expression. CNC manifests itself differently in each and everyone of us – even within a family sharing the same pathogenic mutation, symptoms can vary.  
Feel free to describe your symptoms and the conditions that you personally have been diagnosed with. **Remember, we are only experts on our own CNC journey.**
- b) **When reading posts** remember that we all have our own version of Carney Complex and go through this in different ways. If you notice similarities to someone else's symptoms, make sure to discuss them with/ mention them to your doctors (GP, PCP, Consultant, MDT)<sup>1</sup>.
- c) **Please remember** that some of our members have both physical and emotional conditions. Try to imagine how what you say might make someone else feel.

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<sup>1</sup> We are aware that throughout the world our Medical Care is looked after by a wide range of medical professionals and that in each country we call them different titles. The Admin Team are Swiss and English so we have tried to show here what the titles we have given mean:

**GP:** General Practitioner/ Family Dr

**PCP:** Primary Care Physician

**Consultant:** is a specialist in a certain field of medicine

**MDT:** Multidisciplinary Team

### 3) **Sharing Positive Posts**

If you are part of a support group, let's face it there's probably enough negativity in your life. We all come here for support and to talk about struggles, screenings and surgeries. Most of us have enough anxieties and sometimes we can stir up more concerns when reading what others are going through. These anxieties can be pretty hard to deal with alone.

Help us by sharing the happy moments and times in your life with us as well.

A new baby in the family, a marriage, finishing your education, etc. Share your happy times with us as well as your sad and difficult times.

Even sharing your clear screening test can be a positive thing, it's nice to know that people have clear scans and good news rather than just hearing about the negatives of our screenings.

### 4) **Healthcare/ Medical professionals**

If you work in healthcare or any other medical profession we would ask that once you enter the group you leave your profession aside and just become a member of our group. A person trying their best to cope with the issues dealt to them by Carney Complex.

Please refrain from giving medical advice<sup>2</sup> as we want our members to discuss any health concerns with their own doctors (GP, PCP, Consultant, MDT).

Thank you for your understanding.

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<sup>2</sup> Carney Complex has too many facets for someone to be an expert from treating the few cases in which they possibly had an opportunity to be involved in.

As of 21.05.20 these 'Guidelines' and 'Group Rules' will take effect. 'Guidelines' and 'Group Rules' may be updated in the future.

## Group Rules

### 1) **No medical advice**

This group is for support and sharing experiences, not for medical advice.

You should never substitute professional medical advice, diagnosis or treatment with what you have read in posts/ comments shared in our group. Posts and thoughts expressed here are based on personal experience, are individual and will vary.

Always seek the advice of your physician or other qualified healthcare providers with any questions you may have regarding a medical condition or treatment and before undertaking a new health care regimen. Never disregard professional medical advice or delay in seeking it because of something you have read in this group.

#### a) **Never diagnose**

While we do want to offer support and encouragement to those looking for a diagnosis, we want to be clear that there is never an instance where telling someone they have Carney Complex or any other ailment is ok – even if you are a medical professional.

As we are all aware, just because a condition ‘looks’ like one thing doesn’t mean it is – even if all the symptoms seem to be matching. As much as we know, we only know our own experience. The only person diagnosing our members’ conditions should be their medical teams, not the members of our group.

Carney Complex shares many different symptoms with other diseases such as:

- Peutz-Jeghers syndrome
- MEN1
- PTEN hamartoma syndrome
- Noonan syndrome
- LEOPARD syndrome
- Bannayan-Riley-Ruvalcaba syndrome
- Watson syndrome
- McCune-Albright syndrome
- Neurofibromatosis Type 1 and Type 2
- Beckwith-Wiedemann syndrome
- Li Fraumeni syndrome

This is why sometimes getting a diagnosis can be like running the gauntlet and is the reason why it is so important to get a differential diagnosis<sup>3</sup> done by a medical professional who has the knowledge, the expertise and the experience to do this.

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<sup>3</sup> In medicine, a **differential diagnosis** is the distinguishing of a particular disease or condition from others that present similar clinical features ([https://en.wikipedia.org/wiki/Differential\\_diagnosis](https://en.wikipedia.org/wiki/Differential_diagnosis)).

As of 21.05.20 these ‘Guidelines’ and ‘Group Rules’ will take effect. ‘Guidelines’ and ‘Group Rules’ may be updated in the future.

b) **Medication**

Never tell anyone to take medication or recommend dosages, this should only ever be done by their own medical team.

2) **Research - Knowledge is Power**

This support group and the Admins and Founder firmly believe that while it is great to have support and help, it is very important that each person facing any life altering disease or circumstance, immerse themselves in research, reading and learning as much about their condition as they can. Become your own advocate and create a vast knowledge base of your own. A great place to start is [www.carney-complex.org](http://www.carney-complex.org)

Sometimes people share false information without meaning to. Always make sure to do your research and post only from trustworthy sources, (eg. NIH, Mayo Clinic, Pubmed, WebMed, etc.).

3) **No hate speech or bullying**

Make sure everyone feels safe. Bullying of any kind isn't allowed and degrading comments about things like race, religion, culture, sexual orientation, gender or identity will not be tolerated.

4) **No promotions, spam or soliciting**

Give more than you take from our group. Self-promotion, spam and irrelevant links are not allowed.

a) **Promotions**

Please don't share links to the group (eg. promotional or sales). If you think it might be to the benefit of the whole Carney Complex Community get in touch with the admins before you post to the group – otherwise it will be removed.

b) **Spam**

Will be removed. Please report to the Admins/ Moderators.

c) **Soliciting**

Soliciting in any form is forbidden. We ask all our members to be careful if approached by someone they personally do not know well in real life. Please report to Admins/ Moderators should this happen.

***Disregarding any of the above will result in removal from the group.***

## 5) **Keeping our group safe**

### **What to do if you find a Post that needs attention?**

- Consider all the above things and if you still feel that a Post needs attention or that intervention is required, we ask that you please tag an Admin/ Moderator in the Post so that they can easily find and review it.
- Then send a PM to the Admin/ Moderator that you tagged with details for review.
- Then... move on with a clear conscience
- You personally may not be aware of all circumstances relating to a Post you have reported to us. Our Admin/ Moderators are in constant communication and will deal with each individual situation as is deemed appropriate.

***We rely on our members to help keep an eye out and watch for issues that may arise.*** Thank you for contacting us with your concerns. As you can appreciate we don't always have the opportunity to read every post/ comment in our group and it's with the help of you, our members of the Carney Complex Community, that we can continue to make our group a safe place for all of us.

## 6) **Don't share private information**

Be careful posting your own private health information, do not share medical documents. Do not share anyone else's private medical information outside the group or to other groups. ***What is said in our group, should stay in our group***

## 7) **Voluntary assistance and/ or suggestions**

Our Community is made up of an international membership of people with different professions and as such is a vast pool of knowledge and experience. Admins believe it would be a real disservice to the whole of our membership to not consider under limited conditions sharing suggestions or offers of voluntary assistance.

7.1. If you find yourself in a position where you feel you have a proposition of voluntary assistance or a suggestion you believe could benefit people in the Carney Complex Community, then we have certain conditions.

These are the steps we kindly ask you to take for *every single proposition you want to make:*

- a) First get in touch with an Admin.
- b) Specify in your proposition what it is that you think you can offer.
- c) Be prepared to give verification of license and credentials.
- d) Allow enough time for Admins to validate your proposition and the information provided.

7.2. Admins will dismiss a proposition if:

- a) They feel it goes against any of the group rules and/ or could be to the detriment of our members.
- b) Steps 7.1. a) through d) were not taken.
- c) Verification and information given cannot be verified.
- d) You become uncooperative.

Admin's decision is final. If they do not wish to take your offer any further, no further contact on this matter should be made.

7.3. If your proposal is approved, then an Admin will write a post detailing your proposition. If members are interested they will be asked to contact Admin, who will give them your name and they will be asked to private message you.

7.4. Cause for deletion of a post or removal from the group:

- a) Not following the above steps.
- b) Becoming uncooperative during the validation process.
- c) Mentioning your profession and offering voluntary assistance or suggestions given without following the steps listed under 7.1. a) through d).

Any repetition of disregarding this process will end in removal from the group.

- d) If after contacting you, negative feedback from our members is brought to our attention the post will be deleted and depending on the feedback you could be removed and blocked from the group.

Please be aware that these measures are taken to protect all the members in this group. On the Internet anyone can claim to be anything.

**7.5. Information for our Members**

- a) **Admins/ Moderators will assess the propositions brought to them to the best of their ability but they will not be held responsible in any way for any person/ member accepting assistance and/ or suggestions/ ideas offered to them by anyone in this group.**
- b) **Please be advised to ALWAYS DO YOUR OWN VERIFICATION on this person and what they are offering and to ALWAYS CONSULT AND TAKE ADVICE from your personal physician (as referred to in group rules 1 and 2).**



## Our group Admins/ Moderators

Admins/ Moderators work hard and volunteer much of their free time to help keep our community stay safe. Should you at some point be approached by an Admin/ Moderator please remember they are not trying to police you but rather ensure all our members adhere to the Guidelines and Group Rules. Thinking about how we affect others around us by what we do and say and avoiding self absorption is vital to functioning successfully in society and the community.

Please be kind to them on and off Facebook  
Jennifer, Francesca and Angela