

10 Communication and Process Handling

- Pass on everything that may be of interest. Care professionals have an obligation of confidentiality.
- Show respect in your attitude and behavior.
- Make the situation known if you do not like how a doctor or nurse deals with you.
- Be open about any alternative approach taken on your own in addition to the planned treatment.
- Consider contacting another patient with the same condition.
 - Ask the healthcare provider if there is a patient organization for the disease or search the Internet.
 - A low-threshold medium is Facebook, where there are countless groups for all kinds of conditions and diseases, some open to all and some closed for approved members only.

11 Responsibility

- The doctor or medical specialist will make a treatment proposal and provide as much related information about this as possible.
- The final decision on treatment and use of medicines is taken by you, whenever practically possible.
- The doctors and other caregivers can provide advice when making decisions but ultimately do what feels right for you.

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IMPORTANT ADDRESSES AND LINKS FOR THE GLOBAL CTMTC-OVM ORGANIZATION

Website: www.cmtc.nl

Email: president@cmtc.nl

Children's website: jezz.cmtc.nl



CoC: registration number 40508004

The CMTC-OVM association has the following recognitions:



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Practical tips for a conversation with your healthcare provider

This leaflet aims to increase levels of awareness allowing joint decisions to be made and to encourage both patients and caregivers to decide together on the way ahead.

www.cmtc.nl

PRACTICAL TIPS FOR A CONVERSATION WITH YOUR HEALTHCARE PROVIDER

1 Be informed.

Via the Internet you can search for information about your illness or symptoms. Through Google Search for example, also known as Dr. Google. Do check the source of the results, as not all references found on the Internet are reliable. Material related to CMTC or other vascular conditions can be found at: www.cmtc.nl

2 Be Prepared.

Keep a track of the following for example:

- How you felt recently.
- Whether you have encountered any specific issues.
- If there have been any changes in lifestyle or diet.
- Many healthcare providers and hospitals have a portal that gives access to some of your medical data over the Internet. Access to this can usually be arranged through the healthcare provider's website.

Make a note of any questions you want to ask.

Keeping a diary can also help because you may not know exactly what happened several weeks ago..

3 Preferably do not go alone

- Two listeners will be more effective than one.
- Agree on a role distribution such as who takes part in the conversation and who makes notes.
- Prepare your questions together.

4 Information

- Decide what you want to find out exactly.
- Request lab test results and blood check values.
- Ask which possible treatments are available.
- Check the pros and cons of each possible treatment.
- Clarify which medication should be used now and how this will continue in the future.
- Know what the possible side effects of any medications are.

5 Make notes or record the conversation

- Write down the names of people you speak to.
- Make a note of the date for your records.
- Capture any comments on the possible treatment.
- Note any prescribed medication and directions regarding its use.
- Record the conversation using your smartphone, sound only for example, if this is agreed with the healthcare provider.

6 Ensure clarity

- Ask who will be the principal treatment specialist.
- Also who the contact person will be, how to reach this person and on which days and times.
- Ask if something is not clear. Don't make any assumptions.
- Ask for clarification where necessary, perhaps an example or a diagram.
- Make sure you understand correctly: repeat what is said in your own words.
- Ask for an explanation of medical terms if you need to.
- Ask about any additional written information.

7 For an important decision

- Request time to think about your choices.
- Consider discussing with a nursing specialist or another healthcare professional.
- Check on local clinical experience with the proposed treatment:

- How often has the treatment been performed in the hospital?
 - What were the results for these treatments?
 - What are the risks involved?
 - What can the consequences be in both the short and the long term?
- Are there alternative treatment approaches, and if so which ones?
 - Ask for a second opinion if you have any doubts about your treatment. This can often be arranged through your local doctor for example.

8 Coping with the condition

- Let your specialist doctor or nurse know if you are worried about something or when there is a situation that you may need to discuss.
- If necessary, ask about any guidance options that the hospital / clinic / etc. can offer.
- As a help tool you can use the load meter site (Dutch only) www.lastmeter.nl

9 Psychological and psychosocial effects of living with a rare disease

Living with a rare disease not only has physical consequences but can also have psychological and psychosocial consequences.

- Living with uncertainty is one aspect.
- The underlying condition may not be visible leading others to make unpleasant remarks.
- Self-image and self-confidence can be impacted.
- Learning to handle and accept restrictions.
- Consider the effect on personal relationships such as with your partner, any children you may have or with friends and colleagues.

Your healthcare provider may provide psychological support services and you should at least discuss this possibility with them.

On our website, we have a special section that covers these issues and we also have a medical psychologist in our team.