

SEVEN TIPS

for dealing with a rare disease

Finding constructive ways to deal with a chronic disease is usually a major obstacle for those affected. This is especially true in the case of rare diseases where uncertainty is high and few people are affected.

This checklist is designed to serve as a guide when taking the first steps. The aim is to support those affected in gaining greater control over their new situation and in this way becoming a manager of their own disease. The checklist was created in collaboration with the Global MPN Scientific Foundation and professor Haifa Kathrin Al-Ali, Internist at the University Hospital Halle (Saale) and Director of the Krukenberg Cancer Center Halle.



*This document
is designed to
serve as a guide.*

1.

Inform yourself – the right way!

It's well known that knowledge empowers people. So it's important to be well informed of the various aspects of one's own disease. When gathering information, however, pay attention to the source. Only reliable information helps to properly manage the disease and avoid uncertainties. The internet in particular is a frequent source of misinformation and we're often confronted with superficial knowledge in other situations that can be detrimental to the progression of the disease or quality of life. In Facebook groups especially, it is not uncommon for false information to be spread. Make sure to scrutinize where the information is coming from or verify it in a conversation with your physician.

You'll find reliable information:

- By talking to specialized health care professionals (general and specialist physicians, nursing staff, study nurses etc.)
- As part of the continued public education offers at universities
- At information centers of patient organizations
- At public health facilities

... I read on
the internet ...

Oh ... please
be careful!



*As we all know:
Sometimes it's
hard to ask for help.*



2. Ask your physician

Prepare yourself for the conversation with your physician. Write down your questions and take them with you. Otherwise, you may forget crucial points in the heat of the moment. Consider taking someone along to accompany you. This person can support you in emotional situations and potentially also jot down parts of the conversation. In addition to your questions, it's also advisable to bring along your medical history and findings. Feel free to speak openly – all of your questions are important! No question is too “stupid”. Attached you'll find an extra checklist for the conversation with your physician.

3. Get in touch with others affected

It's not just comforting to see that you're not alone in this unfamiliar situation, which is usually perceived as threatening. In many cases, it's helpful to have an example of how you can overcome challenges to find a suitable solution for yourself.

When people with similar needs come together, it strengthens them in many ways: Alongside exchanging experiences or passing on tips and tricks, those affected also achieve greater visibility and are able to put more weight on their needs and demands.



*A checklist can
be helpful when
talking to a
physician.*

*For more
information, please
refer to the
“Checklist for the
conversation with
your physician”.*

4.

Find support

Everyone is able to better find their way out of a crisis when they have the right support to fall back on. Usually, it's a combination of measures and coping strategies that help those affected to face the disease head-on – or perhaps even to accept it as a friend. After all, it may potentially accompany you throughout your lifetime. Don't hesitate to look for suitable offers or take advantage of them.

Examples:

- Patient organizations
- Partners, family and friends
- Governmental bodies that offer funding, psychological or socio-legal advice
- Psychological support

A wide range of offers is available from the government. Patient organizations often have a good overview, and will be able to provide you with customized advice and help you navigate the jungle of information.



Have the courage to reach out to others who are affected, for support and exchange.

5.

Pay attention to your body

In a crisis situation in particular, it's important to take good care of yourself and keep your body in shape as best you can. Speak to your physician about how you can best care for your body and stay fit. Find out, for example, what type of physical activity is advisable, what applications are sensible and beneficial and what diet is most suitable in your individual case. But also listen to your body if you feel unwell. If this feeling persists for longer, contact your attending physician.

Layout & Illustration: <https://design.renateleitner.com/en>

What can I do for myself and my body?

The illustration shows a person with short blonde hair, wearing a purple long-sleeved shirt and blue pants, sitting cross-legged on a green circular base. A blue thought bubble with a white border is positioned to the right of the person's head, containing the text 'What can I do for myself and my body?'. The background is a light blue gradient with a white circular shape behind the person.

Setting yourself realistic goals can be motivating!



6.

Make use of mental health services

Mental health services can be very helpful for anyone affected. A discussion with a mental health professional can be a safe haven where one is free to express worries and doubts. What's more, mental health experts are trained to find ways out of crisis situations together with their clients and support them in rediscovering their inner sources of power.

Mental health support is offered for example:

- Hospital therapists
- Established psychologists and specialized psychotherapists
- Some patient organizations
- Governmental bodies or community facilities

7.

Take your time to process the diagnosis

The diagnosis may come as a shock. Give yourself and your loved ones time to find a way to deal with the disease.

For more information, get in touch with your physician or pharmacist.

Provided by:

AOP Orphan Pharmaceuticals GmbH
Member of the AOP Health Group

Leopold-Ungar-Platz 2
1190 Vienna, Austria
www.aop-health.com

