

# HOW WILL I COPE MOVING FORWARD?

*A self-help coping guide for patients and close ones.*

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## For Patients

The section for close ones is at the end of the Self-Help Coping Guide.

For Patients

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## This guide

This guide is intended for people who are ill as well as for their close ones. For practical reasons, this guide is divided into sections: the first one includes information for the people who are ill and the second one for their close ones.

**Both sections have been bound into one book, and the second section follows directly on from the first one.**

## A short course on shock and coping with it

A suspected serious disease is already enough to cause a lot of stress and a confirmed diagnosis is always upsetting in one way or another. Despite suspecting it before, it is normal for a confirmed diagnosis to trigger strong emotions or a strong, paralysing feeling.

Adaptation is a long path with many phases and requires both time and patience. Later, after some time has passed, it is possible for the disease to somewhat become a part of your everyday life and something that you just need to accept. You have to go on living with the disease. Tiivi, a young woman with MS, explained that she used to give up easily before, but the disease has forced her to persevere. She wanted to show herself, others and the disease that she can do it.

Even if your self-image and identity change with the disease, and many things need to be left behind, it is good to remember that they will be replaced by other things. When facing difficult situations, never give up hope.

This guide is intended for adults whose life has somehow been affected by a serious disease. Despite an overwhelming feeling of paralysis, you should not let life pass you by. Let's look into how to emerge from the crisis caused by the illness.



See Tiivi's story on YouTube:  
<https://www.youtube.com/watch?v=Kp-5lLawlnA>  
or search for "Tässäkö tämä nyt oli?"  
(Was that it?) (Sanofi Finland)

# For Patients

## A bad feeling

You may have already been coping with symptoms before the disease was diagnosed or named. You may have already ignored tiredness, aches or other undefined symptoms and explained them as being part of daily life. "I am stressed from all the changes taking place at work" or "I am tired because the spring nights are getting lighter and I can't sleep." People are good at creating stories to explain their observations.

When the disease is finally diagnosed, it usually comes as a big shock despite all the premonitions and bad feelings beforehand. Sometimes the disease develops suddenly and completely without any forewarnings, like lightning from a blue sky, leaving very little room for mental adaptation while you are overtaken by the shock and paralysing feeling. In this case, the adaptation begins later, after a quickly initiated therapy. The disease must be accepted as something real – your worst fears have become reality.

## The worst shock of all

Anything unwelcome, uncontrollable and occurring without warning will be upsetting. Falling ill permanently transforms your life.

A disease that suddenly manifests itself is comparable to a traumatic chain of events, such as a life-threatening accident, that can trigger severe stress-related symptoms and predispose people to mental disorders if they persist for a longer time. The disease can alter your functional capability and/or your appearance. Sometimes its treatment can also include procedures that cause anxiety. **It is important to be surrounded by people that will support you.** Although it may be difficult to be "needy", nobody manages alone.

Sometimes getting the diagnosis and the related information can be a relief from the uncertainty but it may also raise more questions, thoughts and emotions. What will happen to me? Worrying about your family might also be eating you up: What about the kids? How will we cope as a family? The disease along with the changes and worry about the future will put a stop to your daily life and be the root cause for **a psychological crisis.**

How long the crisis will last will depend on the person and the situation. Any disease-related setback or other unfortunate events that have nothing to do with the disease will have an impact your reaction to this crisis. How an individual falling ill is influenced, among other things, by his or her personality, earlier life experiences and current life situation.

If the disease stabilises under the treatment regime or if the disease progresses slowly, confusion, fear and uncomfortable emotions will gradually fade away. However, a crisis is a very difficult and emotional experience for the individual in question. Yet it is a gradual process that will ultimately lead to a certain type of stability throughout the different phases. Knowing about these different phases may be helpful in understanding your own behaviour and the behaviour of those close to you. We will now examine the typical adaptation phases a little closer.

## My disease has a name – now what?

When a disease has been identified and named, the challenge begins. The psychological experience that follows receiving a diagnosis can be described by four phases with the first being **a shock phase**, the second **a reaction phase**, the third **a processing phase** and the fourth **a coping phase**.

There are as many ways to adapt to a disease as there are people. Different people experience the phases differently, and there are no clear borders between the phases.



Adaptation to a severe disease usually progresses in phases from the initial shock to a new type of stability.

## First comes the shock

Shock follows immediately after the situation that triggered the crisis. In the shock phase, a person is looking for protection from information that they do not believe they can cope with in order to remain functional.

Learning about a severe disease is the type of news that will lead anybody into a state of crisis. There are many ways to react to shocking news; someone accepts the information calmly, another starts crying, and another may refuse to believe the news. All these reactions reflect some degree of shock and the attempt to protect themselves against it.

If the emotional reaction arises immediately, emotions can vary quickly from disbelief to anger, and from fear to guilt. Thoughts can be desperate: Is that it then? Will I be any good for anything anymore? Will anybody care for me anymore? What do I have to offer now? In every case, falling ill with a serious disease is always a substantial, surprising and scary life-changing event that also affects people close to the patient, such as loved ones, acquaintances and colleagues.

During the shock phase, it is not possible to comprehend the new situation, and many people refuse to accept it altogether. People may alternate between a feeling of paralysis and strong emotions. Any sort of reactions is possible and normal during this phase.

A person who is in a state of shock may feel that their life and physical state have become permanently chaotic. At this time, it would be good to acknowledge that the purpose of mental paralysis is to provide extra time to process substantially important information and to accept unfortunate facts.

## How to handle shock

- It is not good to be alone when in a state of shock. Surround yourself with people and talk about things that keep your mind preoccupied.
- Give yourself time to think about new information.
- Also, remember to rest and eat.
- At this point, do not stress about everyday chores, finding out more information, or how others are doing. There is time for that later.

## Reactions

Following the initial shock, a concept of the illness and its significance begins to emerge. During this time, a person is confused and has a need to talk and to be heard. Talking helps people understand what has happened, its significance and their own emotions.

In the reaction phase, emotions may surface stronger and the feeling of despair can be overwhelming. It is common to experience anxiety and fear as well as feelings of bitterness, shame and guilt. Contracting a disease can be seen as unfair, and people may experience self-pity and anger with themselves. Disease-related topics may constantly invade their thoughts, both while awake and when sleeping.

Different people process being ill differently. One person talks, another remains silent, and another may want to be alone. Sometimes the disease is easier to process once the diagnosis is confirmed and treatment initiated. This is when knowing about the disease and what to expect becomes a reality. Sometimes it is easier to deal with difficult things than with uncertainty.

It may be difficult to find peace, sleep and eat. Difficulty concentrating and unpleasant thoughts as well as questions *why* are constantly and commonly thought about. It is possible that you will have different physical sensations, such as a tremor or nausea.

While in this phase, the situation often feels full of anguish and desperate. However, it is good to remember that strong emotions will ease over time. It may help if the emotions you are feeling can be identified and categorised.

## How to cope when feeling strong reactions

- Talk to other people about how you feel - it will help to structure the situation.
- Familiarising yourself with stories from people in a similar situation may help.
- Try getting back to your everyday chores as soon as you feel it is possible. "Normal" everyday chores will even out turbulent feelings and increase your sense of control.
- Ask for and accept help to cope with daily tasks.
- Remember that all emotions are allowed.
- Suppressing emotions for a long time may make both your mental and physical well-being worse.
- You cannot prevent emotions but they are easier to handle once you identify and accept them.

## Know your emotions

By simply identifying strong emotions, you can alleviate the level of emotional response, making you feel better. Here is a collection of methods that can help you to identify your own emotions.

### Method 1: The sensations behind the emotion

Sometimes it can be difficult to notice and name emotions. Physical sensations associated with emotions may help when identifying them.

- A heavy feeling all over the body may be associated with the feeling of disappointment or depression.
- A restless feeling and, for example, heart palpitations may indicate that you feel nervous or tense due to anticipation.
- Tight shoulders or general muscle tightness may indicate fear, worry or irritation.

What kind of bodily sensations do you have? What kind of thoughts go through your mind at the same time? Do you notice a certain type of repetitive sensation in certain situations, such as on your way to the hospital, when thinking about the future, or when left alone?

### Method 2: The circumstances behind the emotion

Try to recognise three different emotions that you have experienced throughout one day. You can use the list of emotions provided, if needed. Select three emotions from the list and think about or write down situations where you have felt the selected emotions.

- |              |                    |           |
|--------------|--------------------|-----------|
| angry        | feeling ashamed    | insecure  |
| annoyed      | feeling low        | irritated |
| anxious      | feeling of disgust | nervous   |
| delightful   | frustrated         | offended  |
| depressed    | glad               | panicking |
| disappointed | happy              | sad       |
| embarrassed  | humiliated         | scared    |

For example, you can create a table like the following to list your emotions associated with different situations.

Time	Situation	Emotion
14/08 mid-morning	it was difficult to meet other people at the birthday party	frustrated, feeling low

### Method 3: The thoughts behind the emotion

Strong emotions, such as fear, anxiety or sorrow provoke unpleasant thoughts. As you identify and accept the emotions associated with the thoughts crossing your mind, the unpleasant feeling can quickly be alleviated. Unpleasant facts may also become more tolerable when you do not need to suppress or dread the associated emotion.



### Coping process

After some time has passed with seething emotions that have now slowly become more tolerable, it is easier to process what has happened and what is to come. Little by little, the cause of the crisis can be accepted as a real fact. Although it felt difficult and almost impossible in the beginning, most people begin to approach the situation with acceptance.

Although the situation can now be approached more calmly and in a more rational way, strong emotions, especially sorrow, are still there. Thoughts of how the disease will affect their life will slowly emerge. It is hard to think about how the disease will affect functional ability, work or hobbies. It is natural to compare what is happening now and the past, and then mourn over the transformed situation.

Although easier to process, what has happened may still make you feel irritated and you may not enjoy other people's company. This makes many people want to be alone which may temporarily ease the feeling.

However, in the long term, it is better to maintain relationships that are important as you take the difficult steps to adapt.

Slowly the disease will become a part of life, and it begins to be possible to think about it from different aspects. "This will change many things but at least one thing remains constant." Falling ill signifies a turning point in life, and the wider perspective of the disease in how it relates to plans for the future will begin to take form.

The urge to learn more about the disease usually starts during this phase. Many find it soothing to get accurate and current information about the disease. Some days you may feel like you want to completely block out everything regarding the disease. It is important for you to decide what information you want as well as when and in what form you want it. You can gather information by reading, watching videos online or by meeting other people with the disease. It is important to adapt the approach to what suits you and your own strengths.

Although many people feel more stable now than earlier, the mind can still get bogged down from processing this information. For this reason, it can be difficult to concentrate from time to time and your memory may not be as strong. Sometimes the difficulty with concentration and memory are mixed up with possible effects caused by the treatment. It is good to take the time and analyse which effect is caused by what. It is also recommended to ask for any treatment-related instructions and other information in a written form because details you only hear once are easily forgotten. It is good to use different kinds of resources that aid in processing information, such as notes or to-do-lists.

## What helps with the coping process?

- Talk with other people. Things that are hard to accept somehow become more real when you say it out loud or write it down.
- Sharing your experiences, thoughts and emotions with others will structure the things that preoccupy your mind, making it easier for you to understand and process them.
- Talk about the disease and related things outright and head-on. Accepting the facts is necessary for adaptation.
- Even if you would like to crawl up and be alone, **you need other people close to you during a crisis.**

Here are some methods to make it easier to process the new situation.

### Method 1: Capture your thoughts

Keep a diary about your thoughts regarding the illness and any associated emotions. If you have never kept a diary, it can feel unfamiliar and maybe even slightly uncomfortable. Give it a try for a week before you decide whether to continue or not.



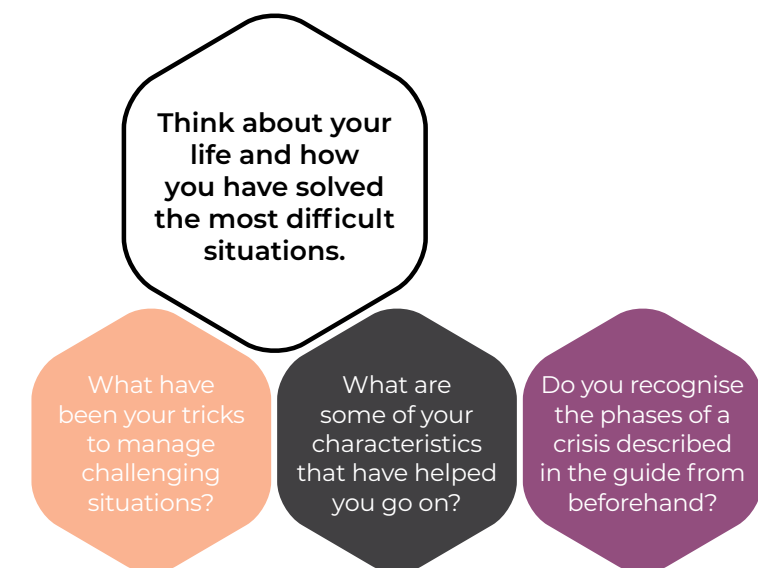
### Method 2: Get informed

Put aside a dedicated amount of time and create a plan on how to gather information about your disease.

- Use a pen and paper or create an electronic checklist to gather information about your disease.
- First list the questions you have in mind. What aspects do you want to learn more about?

- Example questions:
  - What does falling ill with this disease really mean?
  - Is the disease curable? Is it possible to minimise the adverse effects it causes?
  - What is associated with the treatments and medicine?
  - My own medicine – which medicine, which dose, how long will I use this medicine?
  - What if I forget to take my medicine?
  - What things should I keep track of when taking the medicine?
  - Is there an alternative non-pharmaceutical therapy?
  - Is alcohol forbidden?
  - Can I have children?
  - Where can I find advice and help if I have questions?
  - What do I want to talk about at the next visit in a doctor's or nurse's office?  
Make a list of questions for your next doctor's appointment.
  - What would I like to ask someone else who has been in the same situation?
  - Where could I find peer support?
- Think about what kind of help you would need to take care of everyday tasks, to reorganise your life or to find mental strength to continue. This kind of help can, for example, be peer support, adaptation coaching, occupational therapy, physiotherapy, physical education, nutritional consulting, psychotherapy, couple or family therapy, career guidance or information about social benefits and financial tutoring.
- Use reliable sources, such as [www.terveyskylä.fi](http://www.terveyskylä.fi) to find answers to your questions. Pay attention to how reliable the source is and avoid questionable sites. Those hosting these kinds of sites may not have the best intentions.

### Method 3: Me and my crisis



## Coping

### – how will I cope moving forward?

Even if adaptation follows very individual paths, once the crisis is over, your life will become stable again as time passes. During the crisis phase, you had to adopt new coping mechanisms, and you can congratulate yourself by saying “I have made it this far even if it felt like mission impossible at the beginning!”

Although many things have changed, the same person still lives the same life, which started on their birthday and will unfortunately come to an end one day. Constant comparison between the previous “complete” and the current “crashed” life will even out eventually: life still has both good things and bad things.

The psychological work that began with the crisis may have resulted in a very different self-image and concept of life at this phase when compared to the time before the crisis. A serious disease often leads to some degree of life re-evaluation: everyday moments seem more important than before; career and accomplishments lose their importance and there may be a need to spend more time with the family.

Things lost in life because of the disease and therefore a bleaker outlook may still hurt but it is possible to see them as necessary facts. “This is how things are now, and the only way is forward”.

It is possible that your relations are structured differently now: the closest people may have become even closer and there might be a deep feeling of gratitude towards them. The person with the disease may feel guilty that everyday life and hopes for the future in their close circle have also gone because of the disease. On the other hand, conflicts may arise between couples if partners have an unpleasant, for example, too patronizing or pitiful relationship with themselves. It is important to maintain good communication and immediately bring up any emotions that a partner’s certain behaviour brings out in the other.

If there are children, worrying about how they will manage is common. However, children often adapt to a new life situation caused by a disease very well and accept the person who is ill with the symptoms and limitations as the same important person he or she used to be.

Some friendships will become more distant as a result of the disease, either as a result of your or their actions. Some acquaintances may behave in a certain manner that may feel belittling, disparaging or intrusive and may hurt your feelings. Behind horrified or pitiful comments or clumsy support is often a person meaning well and knowing this may make you feel better.

It can be difficult to replace lost relations with new ones. Some people form important connections with people in the same situation, for example through rehabilitation groups and patient associations.

In general, life’s hectic pace may have slowed down and daily routines changed. Normal everyday tasks will require more planning due to possible disability, treatment schedules and the help that you must organise. There may be very little space left for a certain type of spontaneity or ease. It is good to keep up with meaningful activities and hobbies that may help you forget about the disease for a moment.

Falling ill may have resulted in rather large changes to routine everyday tasks. Family responsibilities will be divided in a new way when someone falls ill, and this person may have a hard time accepting the weakened position. For this reason, it can feel very difficult to ask for help.

If depending on others will be part of life in the future, asking for help can feel especially hard. The feeling of independence and having control over your own life are very important for the quality of life, and it can be very difficult to accept losing any of them.

The future may seem uncertain, and fear of disappointment may hinder making any future plans. On the other hand, many people want to consider many different options beforehand to prepare in advance for what the future brings.

When life becomes more stable once again, many people with a serious disease will find that the experience of falling ill was ultimately a change toward a more positive direction, despite the difficult experiences and phases. If life with the disease continues for a long time with its limitations and prognosis, people often experience it as some type of an awakening, forcing the person to stop and listen and to rank the different areas of life according to their importance. In this way, a sad event can be a turning point and a valuable chance to adjust the direction of their life.





Image: © Hannele Salonen-Kvarnström

### How do I make it easier to find stability and maintain it?

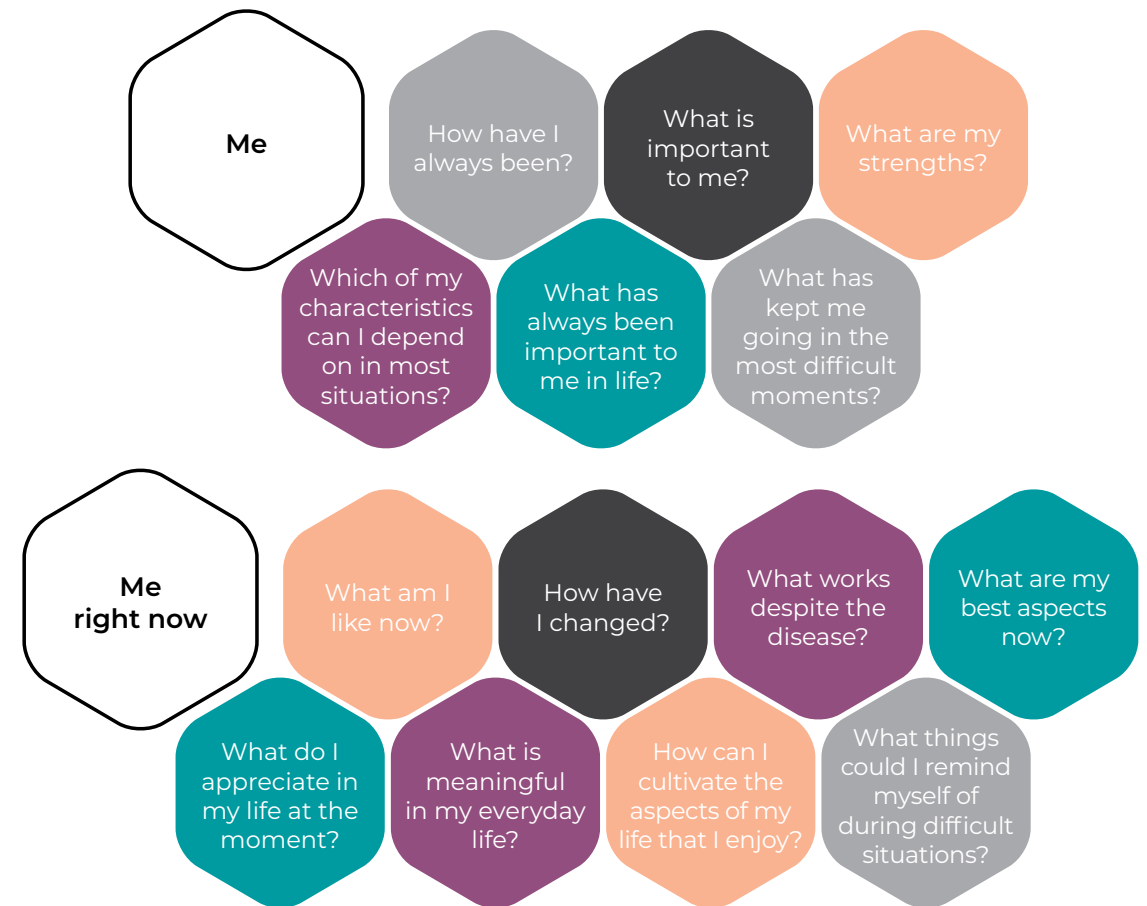
- Pay attention to the things that you haven't had to give up because of the disease. Your thoughts guide your emotions – focusing on positive things will improve your mental well-being on a whole. (See also the next practice.)
- Talk to your loved ones about how you feel about them and what you want from them in an assertive but friendly manner. Independence and the ability to function and influence are very important in your situation, but a close one eager to help and full of worry can easily fail to notice this.
- Also notice that your own behaviour and attitude toward yourself and your disease will affect how others relate to you. If other people have an attitude that you find unpleasant, could you make a difference by doing or saying something differently?
- Cherish meaningful relationships. Let others know that you are grateful when you feel that way. Accept the fact that substantial changes in your life will also create changes in relationships.
- If you feel lonely, try networking with people in a similar situation by using the internet and social media for example.
- Accept that you have needs. People need other people to feel good. Dependency is most often a greater burden to the person who feels it.

- Try also to be active in things that have nothing to do with your disease, possible limitations or disability.
- Think about new activities to replace those you have had to stop doing: are you interested in reading, housework, watching movies or arts and crafts? Participation and getting active will make it easier to adapt to the situation.
- How would you feel about providing peer support to others who are ill? Many people find it highly rewarding to provide peer support in this form.

Here are some methods you can use to help you while figuring out changes that the disease has brought in you and your life.

#### Method 1: New me

Think of the following questions either aloud or in writing.



How does it feel to think about these things? Did you notice anything that you did not come to think of earlier?

## Method 2: Value mapping

Rate on a scale from 1 to 10 the importance of the following areas of life 1) before and 2) how you see them now. 10 means that it is very important to you, and 1 means that it has no importance to you at all.

Area of life	1. Before	2. Now
Family		
Friends and acquaintances		
Me		
Work/studies		
Leisure time		
Hobbies		
Independence		
Relations with others		
Relationship with myself		
Home		
Economy, money		
Physical condition		
Mobility		
Sexuality		
Alcohol and other stimulants		
Other		

Do you notice clear changes in your valuation? What is the aspect of being ill that has caused these changes?

## Where do I find support?

In this section, we talk about the form of support that is usually thought of as the most important: the close family, services provided by healthcare providers and the community, and activities organized by patient associations.

### Family and friends

A functional social network is one of the most important factors in making adaptation easier. Close ones share everyday life with you and they are often highly motivated to help. The support they offer can be encouragement, help with daily tasks and just being there to take part in sharing the general burden.

However, asking for help from family and close friends can often be difficult. Challenging situations can arise if there is an expectation but not the ability to communicate the need. A close one can similarly be confused and clueless about how to offer their assistance. They might be thinking: "Was I too intrusive? Do I try too much, too little, or am I doing something wrong?"

Conflicts are unavoidable in any new situation with new roles. The key factor is open communication with feelings that are clearly voiced. This can be difficult in the beginning but with some practice it will get easier.

People outside the family circle often also offer their help which would be good to accept, if possible. Especially early on, it can be challenging for the person who is ill and other people to initiate a discussion about the disease. It is like the elephant in the room that nobody wants to talk about. Here we provide some helpful suggestions on how to initiate a discussion and how to bring up typical thoughts about the disease as a topic.

### How to speak to others about the disease

- You might have heard that I have got X [name of the disease]. It is alright to talk about it and I honestly hope we can talk about it openly.
- I miss having someone willing to listen and just be around. I do not need any advice or solutions – it would be enough if I can just let my thoughts out.
- I may sound sad and even angry because of my disease but I assure you that my feelings are not directed towards you. I have noticed that talking to others takes the edge off these emotions.
- I am still the same person that I was before falling ill. I appreciate your help tremendously but I do not want overwhelming pity or special treatment.
- It seems like I am not able to do this. Do you think you could give me a hand?
- It is important to me that what I say matters and that I can make my own decisions. I would like you to ask for my opinion and give me yours appropriately, like adults.
- I appreciate it when you say/do... It doesn't feel good when you say/do...
- Do I ever say or do something that hurts your feelings or angers you?

## Welfare and healthcare

Welfare and healthcare professionals constantly meet people in situations like yours. Their knowledge, experience and recommendations are of the utmost value in terms of support you need while in a health crisis.

At best, a healthcare professional can offer support that the family and close friends are not able to provide. In addition to providing reliable medical information, a professional can understand, better than a layman, the needs of a person with a disease to be heard, to feel in control of their own life and to have their freedom of choice respected.

Many important treatment decisions are made within the healthcare system that impact the life of the patient, and therefore it is possible to develop an important and regular relationship with the healthcare staff and site. In addition to improved functionality, rehabilitation also offers support in the adaptation process. Different forms of rehabilitation can give you a rewarding feeling of success and important peer support from others in a similar situation.

Sometimes regular therapy or rehabilitation is not available, and options offered do not feel meaningful. Even in this case, it is recommended to rely on reliable sources and scientific methods in looking for information and services. Very often, things that sound too good to be true are too good to be true.

### Welfare benefits

Many hospitals have social workers who can provide individual guidance and counselling regarding available welfare benefits. They can find out the social benefits and services that correspond to an individual's health status and life situation and help the patient and close ones with the paper work.

The patient's case is supported by the collaboration with other entities, such as the Social Insurance Institution, pension providers, insurance companies, the Employment and Economic Development Office, schools and associations. Social worker services are free and available for all patients and all close ones.

Health and insurance institutes provide advice on how to apply for benefits and how to get rehabilitation. In addition to the above matters, health and insurance Customer Support provides information about reimbursement for medical expenses, income while on sick leave, rehabilitation expenses and healthcare-related travel costs.



Image © Hannele Salonen-Karimström

## Services provided by associations and organisations

If the healthcare provider does not offer information directly, it is worth looking into possible patient associations that focus on your disease and trying to see where they are located and how they work.

Patient associations offer current information about diseases through websites, guides and different events. They may offer adaptation coaching including expert lecturers, workshops and education on how to process emotions and experiences linked to the disease. This may be as remote-day courses that you can complete from home, or courses lasting a few days carried out in rehabilitation centres. Adaptation coaching is most beneficial during the initial shock once the emotional rollercoaster has finished and life has begun to calm down somewhat.

It is often easiest to reach out to other people with the same disease (your peers) through patient associations. It might feel easier to talk to a peer, and you can ask them about issues troubling you, where a “healthy” person may fall short of answers because they lack the experience. Sharing personal experiences can be a great help in adapting to a new situation. You can find peer support near and far, in person-to-person meetings and on the internet.

Patient associations are generally campaigning for the good of the patients and working to advance social interest. Once the worst of the crisis and the need for support have passed, you can become active in an association. This can become an important hobby replacing others you have let go. Patients with the disease are important to an association as representatives providing the experience aspect, who offer valuable support to others with the disease.



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*Johanna Stenberg & Jan-Henry Stenberg*

## For Close Ones



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# For Close Ones

## Someone close to me has fallen seriously ill – what is my role?

When someone falls ill, it almost always concerns other people too; close ones, friends, colleagues. The closer the disease hits, the greater the emotions and thoughts it brings up. Especially close ones may experience similar emotions to the person who is ill when they hear the diagnosis. Also, daily life changes – sometimes temporarily, sometimes more permanently.

People close to the person who is ill will walk their own path to cope with the situation. In addition to the mental burden caused by the crisis, close ones will have to accept a larger responsibility for everyday activities.

The well-being of close ones is important along with good support and treatment of the disease. The purpose of this guide is to provide information and advice regarding how a close one can try to impact their own well-being in a difficult life situation. When the situation becomes too difficult to handle, it is a good idea to look for support from the healthcare system.

## Checklist for someone close to a person who has recently fallen ill

Especially with the acute onset of a disease, practical issues are often left for the close ones to sort out. With emotions in turmoil and scattered thoughts, a close one can also get confused and scared. When feeling down after a shock, taking care of important matters may feel like a heavy burden, and it can be difficult to trust your own memory and attention span. In the beginning, it is better to focus on the most important practical matters. Anything that is not urgent can wait.

**We have gathered tips here for close ones that are good to remember and consider in a crisis situation.**

- Remember that many types of emotions, such as fear and uncertainty, are part of the reaction and completely justified. It is also normal not to get these emotions; every person reacts differently in an emergency.
- Do not be afraid to repeatedly ask for information from a healthcare professional about your loved one's situation, if needed.
- If possible, take part in the loved one's treatment. For example, a close one can often be present at the hospital, attend treatment consultations and visits in a doctor's office.



- If needed, contact the loved one's employer about sick leave and forward any medical certificates to the employer.
- If the recently diagnosed disease is related to an injury or accident, sort out the loved one's insurance information.
- Keep all documents related to the situation, such as medical statements as well as decisions from the health institutes and the insurance company.
- If the person who is ill is not able to take care of their affairs for the time being, a close one should request power of attorney which allows them to be the proxy for the bank as well as issues related with the health institute or an insurance company. If the person is unable to give power of attorney, then a certificate for the above purpose should be requested from a doctor.
- Hospital staff, most often a social worker, will provide support as required, along with information about benefits and services offered by the community.
- If the person who is ill has children, ensure that they are taken care of and that someone can keep them up-to-date in an age-appropriate way, and acknowledge their emotions.
- Take care of your own well-being. Eat, sleep, exercise and meet other people.
- Ask for help at your own healthcare clinic or occupational healthcare clinic, if required. Talking to a professional or someone who is or has been in a similar situation may help.
- Find out contact information for crisis support services in case you or someone else needs external help at some point.

## How to support someone who is ill

Many close ones feel a need to support the person who is ill and in a state of shock while adapting to a new life. Usually this happens naturally, but sometimes a close one can feel inadequate and uncertain about how to give support in the "right" way.

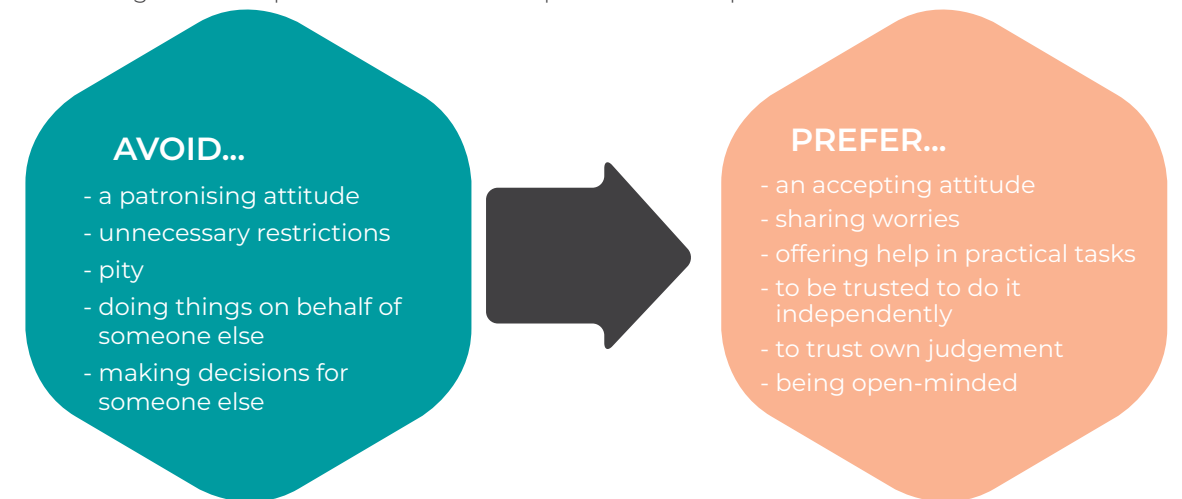
There is no one right way. The person who is ill may ask for company to discuss the situation and their feelings, on the other hand, they may feel the need to be alone to think things through. It is important to respect their requests. It is good to be present, interested and available when needed. On the next page, we have gathered information about how people with the disease typically prefer to be met, and what kind of attitude is good to avoid.

It is important to understand that support means more than just discussing the disease and subsequent crisis. Essential forms of support may be, for example, helping out with household chores, paying attention to other people who are close and just being present. It is alright to ask them directly what they prefer. A person who has been ill for a longer time is likely to need not only support but the feeling of independence and control over their life, and will want to be heard and respected with regard to their decisions.

Although the support provided by close ones is invaluable, it is not always enough. If a close one notices that the ill loved one is clearly suffering and left with insufficient support, it is time to look for professional help.

**Here we have gathered things that are good to know when supporting the someone close to a person who is ill.**

- Everybody reacts differently to a crisis – support must always be provided on the terms of the person who is ill.
- It takes time to adapt to being ill.
- Often, the person with the disease will at some point want to talk. Listening is enough, right answers are not needed and they should not be offered.
- The person who is ill might be numb especially in the beginning and unable to define the help they might need. Be active, be there and offer your support.
- Avoiding behaviour caused by being careful and leaving a person alone is worse than a clumsily worded attempt to console someone.
- It is good to be honest in discussions and to encourage them to also talk about the more unpleasant things.
- The person who is ill must be allowed to repeat things. You should not try to make them forget and think about something else.
- It is also a good idea to offer help with daily tasks, such as grocery shopping or cooking.
- It is also necessary for the person providing support to be able to vent to someone else.
- It is good to keep in mind that there is professional help available.



How to relate to a loved one with a serious disease?



## Falling ill is a crisis for close ones as well

When someone in the family falls ill and life changes, it is a shock for close ones as well and they will need to recover from it. As people are not often ready to process the big picture of upsetting situations right away, close ones also need to adapt to the situation gradually. Knowing the adaptation process may help you to understand your own and the patient's behaviour better.

Initially, close ones and the person who is ill are both shocked and upset, and during this time all sorts of emotions and reactions are possible and understandable. It can be hard to believe that it's true.

Even close ones who belong to the same family can react very differently to upsetting news and a certain type of reaction or readiness to act should not be expected from anyone in a new situation. During the initial phase, both the person with the disease and their close ones will primarily need time and the option to talk about how they feel – when they are ready.

While in a state of shock, it may seem that life has permanently become confusing and unbearable. At that time, it is good to acknowledge that the purpose of mental paralysis is to provide extra time to process substantially important information and to accept unfortunate facts. The situation and how you feel will ultimately become clearer.

Once the initial shock settles, the big picture starts to take a more multi-faceted form and emotions can get stronger. How you feel and your ability to function may suddenly take a downturn. A close one often feels a need to explain and to find someone to blame for the situation. It is common for them to blame themselves. Life can feel very difficult for both the close one and the person who is ill and they can develop different stress-related symptoms, such as nightmares and tense muscles.

In the midst of emotional turmoil, it is good to review your own feelings and thoughts which will also help you make sense of the situation. During this phase, a close one often feels a need to talk and to be heard. It is a good idea to ask and accept help from others. A close one also has the right to get support. It may help, for example, to read about stories from people in a similar situation on the internet.

A factual and coherent understanding of what has happened will take form slowly, but how fast or how slow varies between people. As time passes, the disease will become an accepted fact, and now there will be a desire to process it closer and more rationally. Often it is this stage at the latest when a close one wants to learn everything there is to learn about the disease; what does it mean, where will it lead, and how can it be treated. Information about how others have finally managed to live with the same disease is often found to be invaluable.

However, during this processing phase the disease still seems to have taken over the biggest part of their life. Facing the facts is often associated with sorrow over something lost; the close one who is ill may have changed permanently or earlier integral parts of their daily life and leisure time may have changed. Worrying about the future often preoccupies their mind as well.

It is important that a close one takes care of their own well-being by, for example, continuing to work and have hobbies, if possible, and to meet friends. A close one who is in good health is the best support for others.

### For a close one, it is good to keep in mind that...

- It is nobody's fault when someone is ill.
- The person who is ill needs support and that does not mean curing the disease or removing the disease. It is enough to be around.
- Both the person who is ill and their close ones have the right to feel all sorts of, even conflicting, emotions and thoughts.
- A close one also needs support and someone to talk to.
- Everyone's strength has a limit. The well-being of a close one is their responsibility alone.
- During a difficult life situation, it is important to set aside time for yourself to ensure that you keep in good health.
- Help is available when needed.

The crisis that follows a shocking life event will not last forever. Even in a difficult situation, life usually stabilises itself when an emotional rollercoaster or disease-related issues are no longer the main focus. A close one's disease becomes a part of life, and there are happy moments once more.

## How do I take care of my own well-being?

To be able to keep going, you must find methods and support networks that are right for you. Life should be more than just responsibilities and supporting a close one; there should be meaningful activities, social contact, physical activity and relaxation.

However, taking care of your own well-being should not become an additional stress factor. It is normal that during the initial state of shock there is no time for this, but it is good to give it a thought once you get more time for other things.

Everyone experiences the initial phase that follows the diagnosis differently. Different people recover from stress and relax in various ways. Some people know themselves well and have good stress management skills, others must find and try new ways to release the mental and physical burden.

Some people have other close ones and friends who can offer strength and support. Yet, others lack the natural ability to vent their emotions and thoughts. In this case, support from healthcare professionals or patient associations' peer networks is an option.

Physical well-being is important for you to be able to keep going. Continuing your old sports or trying something new is refreshing for the body and soul. When you feel tired, light exercise or relaxation training is better than any strenuous sports. You should find a balance between exercise and rest that supports your well-being.

It is beneficial for your psychological well-being to try to confront your own emotions. Also, the negative emotions are a part of life, and as such, they do not do any harm to anybody. Emotions cannot be suppressed. If left unprocessed, they can present as tenseness, anxiety, bitterness, cynicism or depression. A heavy emotional state can often be alleviated by identifying and naming unpleasant emotions, thus making you feel better.

It is important to learn to recognise your own emotions and to vent them. You cannot select or turn off emotions but you can control them to a certain degree using thoughts and actions. There is no need to deny unpleasant issues and nor should you, as there is almost always a way to find a positive side to every negative issue and they are worth looking for. Positive thoughts and meaningful activities will give rise to positive emotions, even if you initially feel very low.

Body and mind are tightly interconnected, and therefore relaxing your body will relax your mind. When you relax, your body recovers from being overwhelmed, blood circulation improves, blood pressure and pulse decrease, the stress hormone is not released as much and more of the feel-good endorphin is released. Relaxation effectively alleviates tenseness in the body and mind and provides space to structure your own emotions and thoughts. The ability to relax has a key position in maintaining and recovering your strength.



### Tips on how to support your own well-being:

- Is there something special in your everyday life that helps you to cope and feel good? This could, for example, be a daily nap or a quiet moment in the morning to read the newspaper. Be sure that you have enough time for these. Also think about whether there is something that you know is not good for you and decide to gradually get rid of this habit.
- Also write down things that bother you. Information for your eyes only does not hurt anyone but it allows you to “speak up about” unpleasant facts and also see any positive sides of these issues. Writing things down creates structure for your own feelings and relieves the burden caused by varied emotions, unfinished thoughts and uncertainty.
- Every evening, list three positive things that happened during the day. Anything that you found positive during the day, i.e. single events, news you got or something that has been going on for a longer time. You can write these things down. Make a list for yourself or discuss the list with other people.
- Learn about different relaxation methods, which can be found online, including videos and audio files. For example, try search terms like “relaxation techniques” or “mindfulness techniques”.
- Look for information about the disease you are dealing with. First, make a list of things you would like to find answers to. Make sure to use reliable sources only. It is preferable to use websites from official organisations and brochures that are based on scientific data. Cross check the information with the doctor treating your close one, if needed.
- Learn about the information and activities the patient association for your close one's disease is offering. Participate in something if this is for you.





## Crisis plan

After the initial shock, another unpleasant surprise seems very unwelcome. Especially if the disease is progressive, it may seem appropriate to prepare a crisis plan for the future. Being prepared and writing plans makes logical action possible when surprises strike.

It is good to complete the plan in good time and together with the people fundamentally affected by the situation. All parties should have an understanding about how to act if the situation turns into a crisis once again.

A crisis plan can include wishes of the person who is ill and/or close ones about treatments, powers of attorney, contact information and other details that will help with the coping process in an emergency situation. The plan should be kept safe where it can be found when needed.

Other people find it more comfortable to live one day at a time without specific plans for the future. Everyone makes up their own mind about how to deal with the future. When making plans or when skipping plans altogether, the person who is ill should be heard.

## How will I cope moving forward?

A severe disease brings someone down even if just for a little while. This will easily result in changes in relationships and roles. The head of the family may suddenly become a patient, and the workaholic may become a part-time survivor. Sometimes the disease means giving up things that are important to the person, such as hobbies and work. In the very worst case, this can mean giving up life itself. Losses and reorganisation affect both the person who is ill and their close ones.

Even in the most challenging situations, it is possible to find some sort of stability once the initial crisis settles down. Close ones should acknowledge the changes in roles that occur as a result of the disease and try to retain or return to earlier roles when possible. It is good to let the close one who is now dependent on others be in charge of things that concern them or family matters as far as possible. Along with a caring relationship that develops between couples, they should also maintain the aspects of communication and romance.

People who are ill often find excessive care unpleasant. To maintain autonomy, the person who is ill should be allowed to make independent choices and decide over their own matters as far as possible. The goal is, of course, not to be cold but to show mutual respect and understanding between two adults.

It is good to actively look for new meaningful activities as a replacement for the ones lost. A person's wishes and plans with a progressive disease should be heard, respected and fulfilled even if you find processing them unpleasant. Often a person who is ill does not want to make detailed plans for the future and this should be accepted.

## A step towards a lighter everyday life

Life changes both for the person who is ill and their loved one as a result of the crisis. In this adaptation phase, it is good to take a moment to list their wishes and think about what is important in life. This makes voicing your own needs and wishes to other people possible. For example, try the following exercise.

Take a pen and paper or write down your thoughts using digital media.

1.

Think how you would like your life to be in six months. What about in one year? In five years?

What one thing do you find most important for your own well-being?

2.

Create lists of the following things.

- a. What are the good things you have in your life already?
- b. What things give you and your loved ones pleasure?
- c. What things do you find taxing or stressful?

3.

Do you think you could implement your wishes for the future now? It could involve adding good things and reducing stressful things. Taking even the smallest step can feel surprisingly good!

Return regularly to your notes to check and update them.



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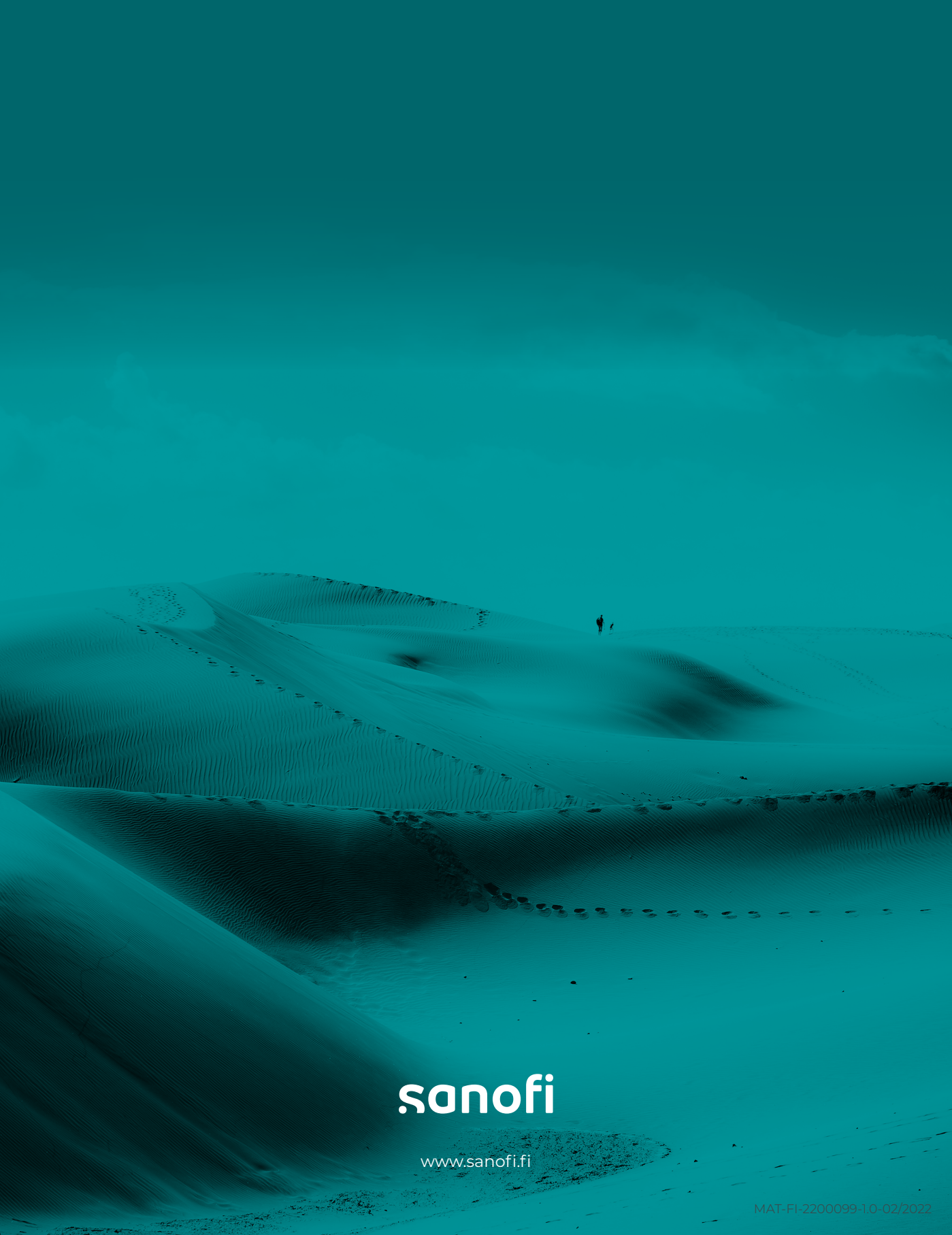
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