

HOW WILL I COPE MOVING FORWARD?

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

Johanna Stenberg & Jan-Henry Stenberg

For Close Ones

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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.



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- 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.

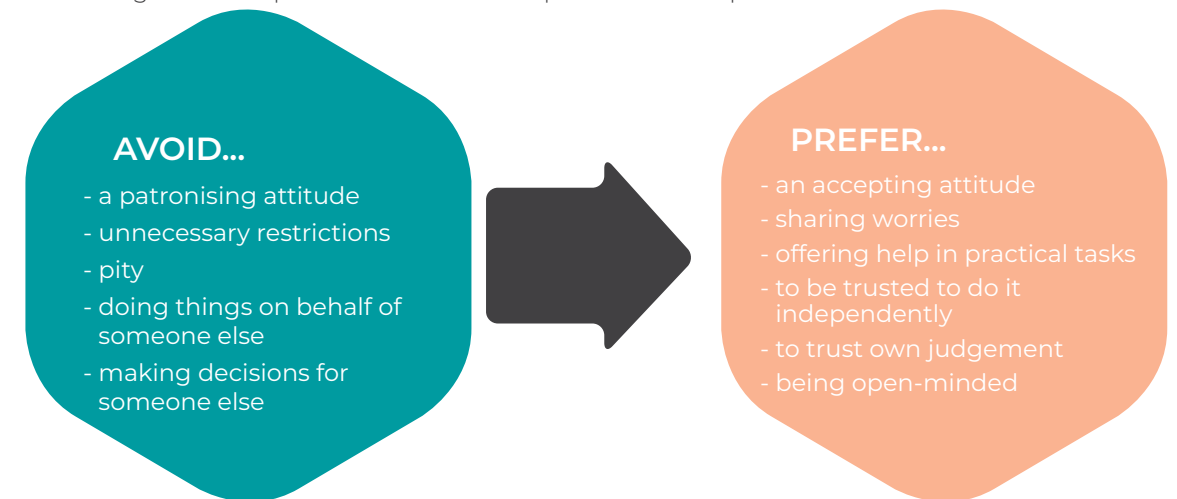
There is no one right way. The person who is ill may ask for company to discuss the situation and their feelings, on the other hand, they may feel the need to be alone to think things through. It is important to respect their requests. It is good to be present, interested and available when needed. On 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.



Image: © Hannele Salonen-Kvarnström

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.



Image: © Hannele Salonen-Karimström

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.



AUTHORS:

Jan-Henry Stenberg

is a Doctor of Philosophy, a psychologist and a teacher-psychotherapist who has helped people change and adapt in his role as a psychologist and psychotherapist. He has worked at HYKS (Helsingin yliopistollinen keskussairaala [Helsinki University Hospital]) in the Psychiatric Clinic and is currently working as the Head of the Psychiatric Division within the field of changing psycho-social therapies. He has been teaching clinical psychology at the University of Helsinki and co-authored several books and articles within the field of psychology.

Johanna Stenberg

is a psychologist who has been working with patients with neurological problems and with clients in rehabilitation who are restructuring their lives. She has gained an insight into the aspect of major life-changing events by observing how people adapt and restructure their lives following an acute illness and accidents.





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