



Life after cardiac arrest

Information for survivors and their loved ones

Published in 2021 by the Swedish Resuscitation Council and the Swedish Heart and Lung Association

Foreword

To those who have experienced a cardiac arrest

This document contains information and advice for survivors of a cardiac arrest. Having suffered a cardiac arrest can be a disorientating experience, whether you are the survivor or a loved one. Research shows that most survivors recover well, but that the time to return to daily life can vary greatly. It's natural to be dazed and confused and have many questions. The information provided here will not answer all of your questions, but aims to give an idea of what can happen, and directions on where to find more help. The information given is broadly general in nature and differences may exist depending on your location, for example, the care able to be offered after a cardiac arrest.

The content is primarily aimed at supporting adult survivors and their loved ones, but may also partly apply to affected children and their loved ones.

In addition to covering areas of the care and recovery process, you will also find quotes from survivors and relatives sharing their personal experiences and reactions. It can be valuable to understand and recognize oneself in someone else's experience.

The Swedish Resuscitation Council (SRC) and the working group for post-resuscitation care are responsible for the content of this material, which is printed and distributed in collaboration with the patient organization The Swedish Heart and Lung Association. This material is also available digitally on the organizations' websites (links below). The information has been reviewed by an extensive group of people with experience in cardiac arrest: healthcare providers, researchers, survivors, and loved ones.

A big thank you to the survivors and loved ones who shared their stories!

More in-depth information on care guidelines can be found on the SRC's website: www.hlr.nu/ward-efter-hjartstopp/.

More information about the Swedish Heart and Lung Association can be found on their website: www.hjart-lung.se.

LIFE AFTER CARDIAC ARREST was published in 2021 by the Swedish Resuscitation Council and the Swedish Heart and Lung Association.

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■ Survivors and loved ones who share their stories:



"I can continue to live life 2.0 with Annmargreth, my children and grandchildren. I am infinitely grateful for that."

Stefan, survivor:

"In September 2017 I had a heart attack during a bicycling holiday on Bornholm. Thanks to my wife Annmargreth, who immediately began CPR and Ole, Erik and Sennait, who came to help, I am alive today and I feel good. I am incredibly grateful to the fantastic initiative from those who saved my life, and often think about what luck I had. Their wise intervention and all the other fantastic healthcare efforts from ambulance staff, the team at Rigshospitalet in Copenhagen, and the continued cardiac care I receive in Sweden means that I can continue to live.

All of the photos that Annmargreth took during the entire time I was sick are so meaningful for me, helped me to process and enabled me to share my story. I was able to return to work full-time and can train more today than I did before my heart attack.

I can continue to live life 2.0 with Annmargreth, my children and grandchildren. I am infinitely grateful for that."

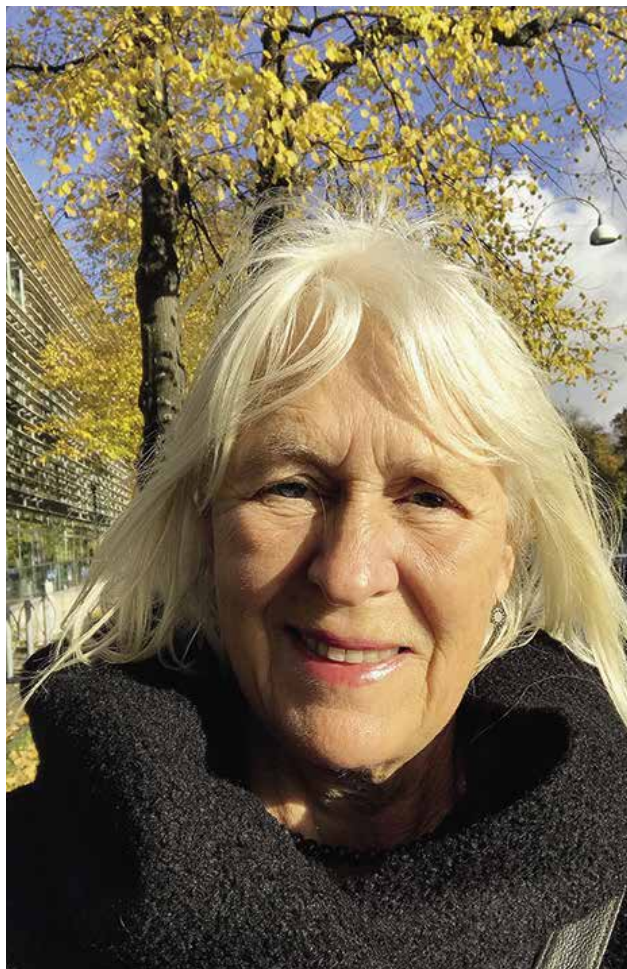
Annmargreth, loved one and lifesaver:

"When Stefan collapsed over his bike, I understood immediately that something serious had happened and I began CPR. For 20 minutes we kept Stefan's heart going until the ambulance arrived. When the time came to transport him to Copenhagen by ambulance helicopter, I began documenting. I photographed a lot over the next few days, to be able to show the pictures to Stefan when he awoke.

I was by his side nearly all the time during the first two months. In the beginning, it was really important for me to accompany him to all clinical visits. When Stefan became healthier and could return to work, I was able to start letting go. Then it was time for me to have problems with my health, in the form of widespread skin problems, eczema and itching.

The doctor explained that similar stress reactions are common after such a serious incident. The problems persisted almost a year. Today, I feel good but still live with an elevated level of tension."

■ Survivors and loved ones who share their stories:



"After almost 24 hours in a coma, where my family didn't know if I would live or die, I woke up."

Ellen, survivor:

"I suffered a sudden cardiac arrest at the age of 38. I was lucky to receive help from both my husband and the "SMS-lifesavers" who came fast. After almost 24 hours in a coma, where my family didn't know if I would live or die, I woke up.

My world became very different from the one I knew before. I was incredibly tired, both physically and mentally. I experienced enormous brain fatigue, difficulties with memory and concentration, sensitivity to sound, and great sadness. My children, husband and relatives all had to adapt to my limitations, and I had to learn to cope with the new me.

Three years have passed and I feel much better. It's been a challenge to deal with my difficulties and learning new strategies for getting through the day. Now, I live a very good life where I've accepted the changes, and adaptations are an important part of making daily life work for me."

Karin, loved one:

"The unthinkable thing that just couldn't happen, happened. Our daughter had a sudden cardiac arrest one morning at home. Thereafter followed a day where we, her parents, husband, and siblings found ourselves in a bubble, in a complete vacuum, in a tiny room for relatives at the intensive care ward.

We lived in complete uncertainty whether she would live or if she would have serious brain damage from the 15 minutes of lack of oxygen during the heart attack. The hospital staff were wonderful and tried to support us in every way.

But there were questions they just couldn't answer. It was a magical moment when she woke out of her coma, looked at us and said, "Where am I? What happened?"

The Swedish Resuscitation Council

The Swedish Resuscitation Council (SRC) is a national knowledge and education organization with the aim of saving lives in the event of sudden cardiac arrest in hospitals and in society. The SRC's vision is that all citizens should be able to perform cardiopulmonary resuscitation (CPR), use a defibrillator, and be able to provide first aid to victims in the event of a sudden cardiac arrest and life-threatening situations. The ultimate goal is that survivors should have the best conditions possible for a good quality of life. The SRC is responsible for Swedish guidelines and training programs for the treatment of cardiac arrest. These are based on international guidelines and treatment recommendations.

More information about the SRC is available at www.hlr.nu



Illustration: KARIN LODIN

The Swedish Heart and Lung Association: “A strong voice for good care”

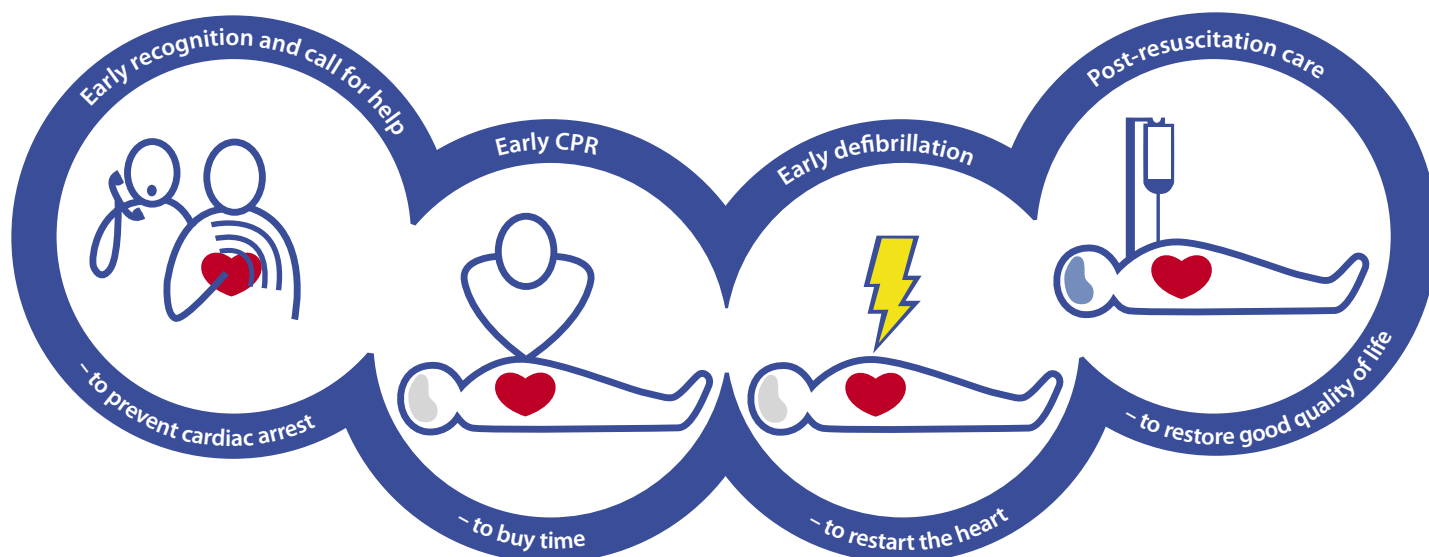
The Swedish Heart and Lung Association is a nationwide patient organization that works to ensure that all people with heart, vascular and lung disease receive the best possible care and quality of life. This is done by informing and educating, lobbying politicians and decision-makers, collaborating with other social actors, supporting patient-selected research, as well as offering customized lifestyle activities for members. The heart of the business is the community and social support that local chapters offer around the country, through their meetings and activities.

The Swedish Heart and Lung Association's most important principles:

- All people with cardiovascular and pulmonary disease should receive an early and correct diagnosis and get treatment quickly.
- Good and equal care, rehabilitation and self-care, regardless of gender, age, ethnicity, income or where in the country you live.
- Good patient information, patient education and more patient influence in care.

The Swedish Heart and Lung Association is non-partisan, non-religious and is run by non-profit forces in chapters at national, county and local levels. The value base is everyone's equal value. The Swedish Heart and Lung Association has been active since 1939 and as of 2021 has approximately 35,000 members, 146 local chapters, 21 county chapters and 6 member organizations, i.e. patient and interest organizations for a special diagnosis.

More information on the Swedish Heart and Lung Association at www.hjart-lung.se



The Chain of Survival

Every year in Sweden, approximately 8,500 people receive CPR after suffering a cardiac arrest. Of these, approximately 1,500 lives are saved. Cardiac arrest means that the heart's ability to pump ceases. This can be caused by various disorders of the heart rhythm, such as chaotic electrical activity in the heart's chambers, or that the heart's activity ceases completely. An unexpected cardiac arrest is a sudden, dramatic event, whether it occurs in a hospital, out in public, or at home.

8500

people receive CPR every year after suffering a cardiac arrest.

The chance of survival depends on a series of measures that are usually described as links in a chain, "The Chain of Survival."

- Early recognition and call for help – to prevent cardiac arrest
- Early CPR – to buy time
- Early defibrillation – to restart the heart
- Post-resuscitation care – to restore good quality of life

The time to treatment is crucial for whether a life can be saved. The focus of this brochure will be the fourth link, which includes follow-up and rehabilitation.

Early recognition and call for help – to prevent cardiac arrest

Sudden pain in the center of the chest or severe shortness of breath are common symptoms of myocardial infarction. Myocardial infarction is the most common cause of cardiac arrest. It is therefore important to immediately call for an ambulance if such symptoms appear. Early recognition of cardiac arrest and call for help (112) is crucial to be able to dispatch an ambulance, to start CPR and to provide early use of an AED. The dispatcher can provide instructions of how to perform CPR before the emergency medical services arrives. Within healthcare, it is important to have systems to recognize patient deterioration to be able to prevent cardiac arrest. When an in-hospital cardiac arrest occurs, a medical emergency team is often called upon by using an internal alarm system.



Early CPR – to buy time

Early CPR increases the chance of survival by 2-3 times compared to if no CPR is started before the ambulance arrives. If a person suffers from a cardiac arrest, CPR should be started immediately. Through CPR, a method consisting of chest compressions and rescue breaths, blood is oxygenated and pumped around to the body's organs while waiting for a defibrillator or other treatment. According to current guidelines, a combination of 30 chest compressions and 2 rescue breaths should be given. The emergency operator can help untrained lifesavers with instructions by phone. In these cases, only chest compressions are recommended. In hospitals and ambulances, a compression device is sometimes used that provides mechanical compressions.



Early defibrillation – to restart the heart

Defibrillation means that an electrical shock is delivered to the heart using a defibrillator and electrodes that are placed on the chest. The shock can break electrical chaos (ventricular fibrillation) and help to restart the heart. Defibrillation within 3 minutes can, in some cases, increase the chance of survival up to 70%.



Post-resuscitation care – to restore a good quality of life

Emergency care and time in the intensive care unit

Important measures in the ambulance and the hospital after resuscitation are to monitor vital functions, as well as to identify and treat the cause of cardiac arrest. After a cardiac arrest, a shorter or extended period of unconsciousness often follows. Therefore, post-resuscitation care is most often carried out in the intensive care unit (ICU), where advanced equipment is used to monitor the heart and other important organs. A nurse or nurse's aide is always present in the patient's room to be able to detect and remedy any complications immediately.

Depending on the course of events and the cause of the cardiac arrest, the care at the ICU is adapted to the patient's needs. The care includes breathing assistance with a respirator and control of body temperature to avoid fever. If a heart attack (myocardial infarction - blockage in the coronary arteries of the heart) is the suspected cause of the cardiac arrest, a coronary X-ray and, if necessary, balloon dilation is performed.

This is a difficult time for the loved ones of those who have experienced a cardiac arrest, and the uncertainty is great, the questions are many and the answers few. During the first 24 hours after a cardiac arrest, doctors cannot give a definite prognosis. The information to loved ones becomes more detailed and the prognosis more secure as the days pass following resuscitation. There is a risk that brain damage develops due to the lack of oxygen that occurs in connection with cardiac arrest. Once cardiac function has stabilized, the extent of any brain damage is the most important factor to assess. A more well-founded assessment can usually be made 3-4 days after the cardiac arrest, although this can take longer.

Whilst in the ICU, patients who show signs of waking can often go in and out of consciousness. Many become increasingly aware of time and space and eventually recognize their loved ones. It is not certain that those who wake up during the time at ICU will remember it later. Instead, it is often later in the hospital's cardiac care ward that conscious awakening takes place. Some patients describe the time at the ICU as a large black hole, many have diffuse memory images. Time spent at the ICU varies. Most patients spend two to three days there, some up to several weeks. A diary of the care given at the ICU and in the hospital ward can help to later fill in memory gaps. Things

that may have seemed insignificant may have much more meaning later in the recovery phase. The diary is written by the staff at the ICU, but medical staff may also encourage loved ones to write in it. The diary may also contain photos from this time of care.

"I have a memory gap. Ten days are lost from my memory, but fortunately, they are documented in the diary. For me, it was valuable to read the diary together with my son, who wrote a lot in it."

"When I look at the pictures, it becomes really clear and distinct. I've been through this. In the pictures, I have a cooling suit on. I immediately think that it was lucky that I was unconscious then. I'm otherwise very sensitive to cold."

"When I read the diary for the first time I nearly sat and cried. One of my sons had written, 'You were as cold as if you were almost dead.' He seemed to have begun to prepare himself for that."

Loved ones play an important role at the hospital by being present and close by. Children are often welcome to visit while the patient is being cared for in the ICU. Studies have shown that children can cope well when visiting critically ill loved ones. They should be offered the opportunity to visit their loved ones and have the chance to ask their own questions of the medical staff.

"It was agonizing to just sit and wait. I shielded myself and was prepared to be focused on if or when something new happened. Holding my wife's hand was a way to transfer energy from me to her."

"I did not know if I would become a widow or if I would get to bring my husband home again and, if so, in what condition? How would it be with the whole family? It was a very anxious time not to know what would happen. The doctors had a hard time saying anything about the prognosis, but otherwise provided information about everything they could."

"My thoughts initially revolved around I only have him. He's just graduated. How can that happen? The emergency room doctor said 'he will fix this'. But at the same time, I knew he couldn't know either! At the ICU, they said 'he's in good condition to cope



with what's happened, but we cannot know if his brain has been damaged.' The thoughts then started to spin around, what if he's brain-damaged!"

In the hospital cardiac care ward

Moving from the ICU to a cardiac care ward is for many a sign of recovery, but some may also experience anxiety and insecurity in leaving the safe and supervised ICU environment. In the cardiac care ward, the physical improvements often come quickly, but many feel that short-term memory is impaired. It can be a sign that the brain has been affected by cardiac arrest, but at this stage can also be due to a variety of factors, such as medication side effects, crisis reaction, lack of sleep, fatigue, and pain. It is important to remember that rest and breaks are important, and that information may need to be repeated several times, or written down. Most people do not remember what happened. It can feel uncomfortable not to remember what you have been through, or maybe the time before. In the quotes below, some loved ones share their experiences.

"The improvements came very quickly. My wife was up and walking, but her short-term memory was probably not really there. She asked the same questions over and over. At first, she didn't know where she was."

"My husband remembers the time spent in the cardiac care ward as a dizzying experience. He tested the limits, wanted to leave the ward without supervision. But then he felt insecure and soon returned."

It is natural to have thoughts about how things will be in the days ahead. A lot of information is needed to understand and be able to cope with what has happened. Further investigation into what triggered the cardiac arrest, the need for medication and different types of risk assessments take place either in the ward or after discharge. Depending on the cause of the cardiac arrest, some patients may also receive an implantable defibrillator (ICD) and/or a pacemaker.

Before returning home from the hospital, an assessment of any difficulties and reactions related to the cardiac arrest is recommended, to determine further rehabilitation needs.

Care following cardiac arrest should strive to be person-centered, which means that it is based on the patient's explanations and health needs and is planned together with the patient and their loved ones. In connection with discharge, conversations about, for example, sick leave, medicines, continued follow-up, contact information and planned care interventions should be carried out. During the conversation, it's good if a loved one can participate as there can be a lot of information to take in.

The SRC guidelines for follow-up after cardiac arrest recommend that, if possible, a special contact person be designated at the time of discharge. However, the possibilities vary depending on local conditions. The SRC has published a short informational brochure that is intended to be printed and shared. It is available to download on the website hlr.nu.

www.hlr.nu/vard-efter-hjartstopp/

Follow-up and rehabilitation

Various professions and competencies are involved in follow-up and rehabilitation after cardiac arrest. Representatives from cardiology, ICU, neurology, and physiotherapy are often engaged in care. Other professionals such as occupational therapists, neuropsychologists or counselors are involved as needed. This can look different depending on where you are in the country, but it is important that local contacts are established and collaborations in the follow up are built.

All patients should be offered a return visit to the hospital within 1-3 months after discharge. Such follow-ups usually takes place at a cardiac clinic and/or post ICU-clinic. Follow-up of children and their relatives should initially be organized by a specialist.

Swedish CPR Council guidelines state that a structured follow-up should be held to confirm that the patients and relatives have received sufficient information on the cause of cardiac arrest, the course of events, sick leave, driving, etc.

Furthermore, an examination is done of any remaining difficulties related to the cardiac arrest, such as physical fatigue, brain fatigue, pain, physical limitations, cognitive (mental) or emotional difficulties. If the need for extra

support measures is identified, the follow-up should lead to a plan for further investigation and possible rehabilitation. Cooperation with primary care is important as much of the support is likely to take place there.

Those who have received an ICD/pacemaker are regularly called to the hospital's cardiac clinic for check-ups.

The guidelines can be read on the Swedish CPR Council's website hlr.nu.

www.hlr.nu/ward-efter-hjartstopp/

The rehabilitation plan depends largely on the cause of the cardiac arrest and the possible consequences caused by the event. Since myocardial infarctions and other heart diseases cause most cardiac arrests, an important part of post-care is to reduce the risk of developing new heart problems, so-called secondary prevention. It can consist of, for example, drugs that lower blood pressure and blood fats, help to quit smoking, physical activity, and stress management. Some cardiac arrest survivors are offered to train in special "heart groups" with the support of a physiotherapist for a period of time. Many hospitals also offer "cardiac schools", which are a series of lectures in which different professional groups participate.

In the case that cognitive abilities are affected, for example, if there are effects on memory, concentration, or ability to plan, continued assessment by an occupational therapist or neuropsychologist may be warranted. It is important to try to understand where these difficulties arise from. Part of the problem can be related to brain damage that occurred during the cardiac arrest, but it can also depend on other factors such as physical exhaustion, brain fatigue, poor sleep, or emotional difficulties.

Different strategies and aids can make daily life easier. These can include different types of memory support devices such as alarms, calendars or to-do lists, but they can also involve adapting to daily life and doing things differently. For the few survivors who have suffered severe brain damage, care and support at a specialized rehabilitation unit and/or cognitive medical unit may be required.

Because emotional reactions are not uncommon, it is appropriate to offer both patients and loved ones the support of a counselor or psychologist who can assess the need for additional support.







Back to daily life

To have had a cardiac arrest is a disorientating experience, regardless of if you are the survivor or their loved one. Everyone reacts differently. Most survivors recover well and can live a completely normal life, but it often takes time. Difficulties with memory, concentration, fatigue and emotional reactions are relatively common, especially in the beginning. Recovery times vary. The biggest improvements happen in the first couple of months but often continue for a prolonged period.

It is important that loved ones are involved in follow-up and rehabilitation. If you or your loved one suffers a cardiac arrest, it can trigger a crisis reaction, which is perfectly normal. People can react very differently to the same events and situations, but there is help available. More information is found at 1177, via your local health center.

If there are younger children in a family where someone has been affected, it is important that the school/preschool is informed about what has happened, both to meet and be able to support the child in the best way possible. Traumatic experiences can stay with children for a long time and create new behaviors that those around them must be able to understand and handle. In the beginning, some patients and relatives testify to a feeling of uncertainty and insecurity, but over time, improvements

at various levels contribute to an increased sense of security. In the quotes below, survivors and their loved ones share such feelings.

"In the beginning, I was worried. I could not sleep at night, I was afraid that my heart would stop when I fell asleep. But it passed after the first two weeks."

"It was insecurity. Just the feeling that now all surveillance was gone. What would we do if something happened? Everyone in the family was afraid that something would happen, that his heart would stop again. The risk is minimal, they had said at the hospital. But when my husband lay down on the sofa to rest, one of the children was usually nearby and checked that his chest was moving, that he was breathing."

"The doctors do not know why I had a cardiac arrest despite all the examinations. I have to cope with that."

"I didn't dare to walk alone in my usual exercise track at first. Since I wasn't allowed to drive, I took the bus into town. There I walked around to be among people if something were to happen. A week later, I got tired of it and set out on the exercise track with poles, a mobile phone and Nitrospray for my daily walks."



“An ICD can mean security for both patient and relatives. For some patients, like myself, it’s also a constant reminder of what’s happened, a gratitude that I’m alive but also a sadness about having the need for an ICD.”

Exactly when it is appropriate to return to work depends on the type of job, how fast the recovery has gone, and the eventual consequences of the cardiac arrest. It is a judgement that must be adapted to the person’s needs. Return to work can be a step-by-step process. In the beginning, it can be helpful to include one day of rest per week. This would need to be carried out with the guidance of the Swedish Social Insurance Agency (Försäkringskassan). Sometimes, Försäkringskassan can call a reconciliation meeting before returning to work. The purpose of this meeting is to plan how the return will take place in the best way, based on individual conditions, and to create a plan going forward.

In addition to the person concerned, any close relatives, employers, doctors who approve the sick leave, and Försäkringskassan participate in such a meeting. Sometimes people in other professions that know your strengths and weaknesses can also participate, such as an

occupational therapist. Each health center should have a rehabilitation coordinator who can provide you with additional support.

It is common to be recommended to refrain from driving for a period of time after a cardiac arrest. It is not the same as having the driver’s license revoked, but the recommendation should be followed. The regulations for revocation of driving licenses due to medical reasons can be found in the Swedish Transport Administration’s (Transportstyrelsen) collection of statutes. It is the doctor, usually, a cardiologist, who makes the decision. How long the recommended driving ban applies depends on the person’s condition. Once you are allowed to start driving again, it’s important to be especially careful at first, as well as to be observant of how fatigue affects your driving. If the cardiac arrest survivor drives commercial transport, there may be special rules to consider.

“Today, I think it was a good decision not to be allowed to drive a car immediately after going through such a big dizzying event. It takes some time for the brain to get going again. I noticed this myself in my ability to read and solve crossword puzzles. You can be a danger both to yourself and to those you share the road with.”



Health and quality of life in cardiac arrest survivors

Many people who have experienced a cardiac arrest will go on to live a completely normal life. Most people recover well, but recovery times vary. Research that investigated health and quality of life in cardiac arrest survivors shows that the majority of survivors rate their health and quality of life as good six months after the event. Their self-rated health and quality of life are equivalent compared to so-called normal populations, as in the general population in Sweden. Some survivors may find that they appreciate life more, prioritize what is truly meaningful, stress less, and feel that they have a second chance.

"I have a completely different perspective on life today."

"Actually, I wouldn't be here today. If I'm here now, then it means that it is something I have to take care of. Nothing I can neglect."

Even though the majority of survivors rate their health and quality of life as good, the experiences of life after cardiac arrest are varied and individual. Being part of a "near-death experience" like a cardiac arrest can mean an increased awareness of one's own vulnerability. In the beginning, some survivors may experience a search for meaning and control.

The most common health problems reported by survivors of cardiac arrest are emotional reactions, cognitive difficulties, and fatigue. Fatigue means "an experience of exhaustion that seems disproportionate to the patient's activity level." In the beginning, many also report pain in the chest area after receiving CPR.

The emotional reactions can for example consist of worry/anxiety, depression and stress reactions. Some suffer from panic disorder, which can be very unpleasant and cause sudden symptoms such as palpitations, tingling in the body, difficulty breathing, dizziness, nausea, and cold sweats. The bodily reactions to panic disorder are similar to those seen in heart attacks. They are scary and very unpleasant, but harmless. If the symptoms are so strong that you seek hospital care, they usually decrease when a test is done that shows that there is nothing wrong with the heart.

If anxiety attacks recur, they can be treated with either

medication or cognitive behavioral therapy (CBT). CBT can be used for stress-related problems, sleep problems, anxiety, panic disorder and depression.

"It was quite identical, although it never turned black. I never fainted. I had palpitations, cold sweats, shortness of breath, pressure, and anxiety in my chest. I never thought that it could be the brain that played a prank on me. I sought emergency care and was declared healthy a few hours later."

"After a few months of waiting for CBT treatment, I bought a book about CBT for self-treatment. I trained myself to stop the attacks when they came and to understand that the attacks are a game that my head was playing. When I felt that an attack was coming, I somehow shook it off by changing my thoughts. I got rid of my problems after a while."

"She had severe dizziness, probably linked to anxiety. One gave over to the other. She could not do errands, go shopping, not even go to a grocery store because of dizziness and anxiety."

Cognitive (mental) problems can be a consequence of brain damage but they can also be linked to other factors such as poor sleep, fatigue or depression. The most common cognitive problems are impaired memory, ability to concentrate, speed of thought, and ability to plan. Many also experience brain fatigue and lack of energy. Brain fatigue is often linked to a brain injury because damage requires the brain to use more energy to process information.

A person with cognitive problems and/or brain fatigue is more tired than before and is more affected by too little sleep, exertion, stress, or low blood sugar. When the brain is bombarded with stimulation, it can become overloaded and fail to function normally. It's important to understand that brain fatigue does not have to be due to brain damage, and that brain fatigue itself can lead to the experience of cognitive problems.

When we are tired, we find it difficult to concentrate and this can affect our memory. Minimizing the consequences of fatigue is therefore important to make daily life work. The environment should be calm and structured with the possibility of regular breaks to alternate rest and activity. Rest allows many to be more active, and resting in »



time can be important in reducing recovery time. Attitudes and expectations from the outside world and one-self can mean demands that are difficult to handle. It is important to prioritize and return to activities gradually.

The problems are often only noticed when you start working. Many survivors in recovery want to do too much. Part of continuing improvement may be in learning to deal with your problem of energy deficiency, which usually improves over time.

"I quickly discovered that not everything was as usual. My memory was catastrophically bad. I forgot things like, for example, that I was going to throw out the garbage. I stood there with the garbage bag in my hand and wondered what I should do. Embarrassing. I didn't want to tell anyone about my problems."

"I do have some memory problems but my daily life works for me."

"I can do the exact same things as before, but now I must do them one by one. I can't juggle so many balls at once anymore."

"I had a diary throughout the first year as a memory aid. My memory was so bad I didn't remember what I did the day before or the day before yesterday. Last week or longer back was as if it had not existed. The diary also helped me flip back to see progress and improvements. I often flipped back a month to read how I felt then and could see improvements almost every time, which made me hopeful."

The needs for follow-up and/or rehabilitation are varied. This is partly due to the extent of brain damage but also to more individual factors. There are those who manage their daily lives well despite any memory problems, difficulty concentrating or fatigue. Many have no cognitive problems at all, while others have a concern that "something is different." For those affected, it can be important



to know that the condition is not getting worse, and that there is help available.

Those who experience cognitive problems must first become aware of what is not working as before, and then begin to learn to use compensatory strategies, such as finding alternative solutions. Occupational therapists are key people and are often available in primary care. There are also special rehabilitation clinics that offer a thorough investigation of the problems with the help of a multi-professional team. The investigation is used to design an individual rehabilitation plan. Efforts to achieve set goals can then include a more intensive training period or more long-term support in various forms, such as to return to work or a functioning daily life.

One thing that is commonly expressed by many who have survived a cardiac arrest is that they feel a great deal of gratitude towards the person or persons who saved their

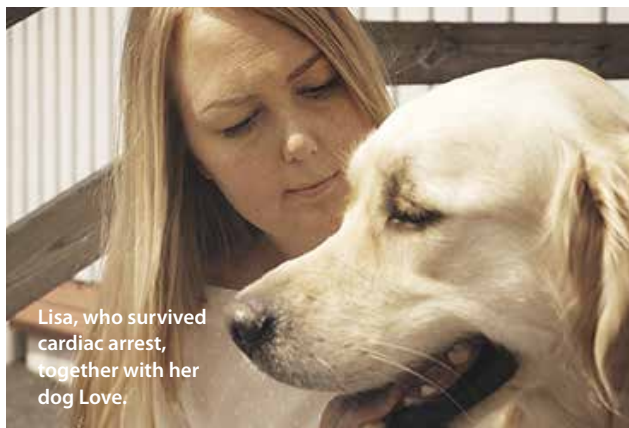
lives. They want to do what they can to spread the word about how important it is for as many people as possible to start CPR on the day it is suddenly needed.

"I decided to leave what happened behind me and move on. The initiative with my own website is my way of being able to help others. I want to make my municipality heart-safe and have started a fundraiser to get a defibrillator. My co-workers and friends are educated and today I blog about my life."

"Our daughter contacted the health service some time after the cardiac arrest to try to get in touch with the two SMS lifesavers who came to the home when they received the alarm. The lifesavers appreciated getting feedback on how it went, and their meeting with our daughter and her husband helped her, her husband, and the lifesavers themselves to process what they had been through."

Health and quality of life of loved ones

Being close to someone who has suffered a cardiac arrest can be very stressful, not least for those who were present during the cardiac arrest and also may have performed life-saving treatment. The very first time at the ICU after resuscitation and the time in connection with the patient waking out of unconsciousness can often be experienced as insecure and chaotic for the patient's loved ones. The role of loved ones during the period of recovery after a cardiac arrest can vary greatly. Many become an important support for the survivor by helping them to solve everyday problems, assisting with reminders and their memory, providing company and encouragement in daily life. Also listening, responding to reactions and providing physical support. At the same time, loved ones often have their own trauma to cope with. Many people find that they, quite naturally, are careful to show their feelings so as not to worry the person who survived the cardiac arrest. The loved one's own needs often come second in the beginning, and their emotional reactions can show up much later. The whole family's life changes and, for example, their children and grandchildren are sometimes forgotten. They also have a crisis to handle and may not want to show that they are unwell.



Lisa, who survived cardiac arrest, together with her dog Love.

"You have to find strategies to deal with anxiety for the survivor, partly for a new cardiac arrest, but also for the subtle cognitive changes. I was offered counseling in the beginning, but it was only after we had come through the first half of the year that I began to be receptive. Until then, it was so much about practical things, making daily life work."

"In our family, our six-year-old understood that dad was ill and in hospital. When dad came home, everything was fine. Our son seemed to have a very easy time dealing with the situation. However, he reacted to his mother being so tired and exhausted. There were others who had to help take care of him. Our daughter, 13 years old, was present when it happened. She had a hard time putting her feelings into words; she did not want to talk. In the end, we took the initiative to contact a child psychologist. They did an examination about six months later. Today I think it was an awful experience for her, but at the same time maybe also enriching. When our oldest daughter saw how her father was making progress and approaching his old self, it was good for her too."

"Our 3-year-old granddaughter carried a fear and insecurity for a very long time after witnessing her mother's cardiac arrest. She could not let go of her mother for a moment, and would be with her in every room, all day."

"We have found our way back to our previous habits. We do everything we did before without feeling any restrictions. We have played golf again, visited the summer cottage to pick cloudbberries, and also took part in a bus trip abroad."

Few studies have examined the health and quality of life of the loved ones of cardiac arrest survivors. The available research shows that most loved ones rate their overall health and quality of life as good six months after the event. On the other hand, stress and emotional reactions seem to be as common in loved ones as in the person who survived the cardiac arrest, especially among those who witnessed the event at home.





The Swedish Heart and Lung Association

To suffer from a cardiac arrest or a heart, vascular or lung disease is to be reminded of the fragility of life. Fortunately, there are ways back to an active and meaningful life. The Swedish Heart and Lung Association exists to provide advice and support.

Community

After a cardiac arrest, it is easy to feel lonely and abandoned. But the good life exists - even if it's difficult to see it sometimes. Getting back to an active life takes time. Being with people who are in the same situation makes recovery both easier and faster. In local chapters, there are opportunities to make new friends for life. These chapters organize activities, lectures, opportunities to meet and socialize, share knowledge, experiences, community, and joy. Loved ones are always welcome to take part in the community. Being able to meet others who are in a similar situation is an invaluable asset.

Lifestyle

As a member of the Swedish Heart and Lung Association, you can get help with lifestyle changes that lead to better health, participation in the meetings and much more. Many of the local chapters have health coaches who are tasked with supporting the members on the path to new habits and better health. The focus is on what health is for the individuals and what they can do to feel as good as possible. Lifestyle changes rarely happen overnight, rather by creating good habits

and sticking to them. Often one good habit leads to the next; if you move, sitting still decreases and if you eat your fill of good food, the need for sweetness decreases. A good lifestyle is the result of many small choices in daily life.

The Swedish Heart and Lung Association offers educational materials and training programs that are adapted for people who have had a cardiac arrest or are living with heart, vascular or lung disease. Of course, it is the individual who decides which activities they wish to participate in, at what level and how often. Loved ones are more than welcome to participate. The programs are led by group leaders in the local chapters and can include medical yoga, exercise and water aerobics, boules, Nordic walking, and strength training.

Lectures

To spread knowledge about cardiac arrest, cardiovascular and lung disease among members and the general public, local chapters arrange lectures on various topics. Invited speakers include researchers, doctors, nurses, physiotherapists, dietitians, psychologists, occupational therapists, and counselors.

Cardiopulmonary resuscitation (CPR)

The local chapters' CPR instructors offer courses in cardiopulmonary resuscitation for members. Opportunities are also provided for those members who wish to train as CPR instructors. The Swedish Heart and Lung Association follows the SRC's guidelines.



Peer support network for cardiac arrest survivors and their loved ones

Contact with others in similar situations is important for getting support and exchanging experiences. A national network has been formed by a number of survivors affected and their loved ones, together with the SRC and the Swedish Heart and Lung Association. You can contact the network via Facebook or by email to the Swedish Heart and Lung Association. The Swedish Heart and Lung Association also offers network support through its local chapters.

Facebook: www.facebook.com/groups/hjartstopp

Email address: overlevarehjartstopp@hjärt-lung.se

Website: www.hjart-lung.se/natverket-for-overlevare

"I received information about a patient association at the hospital. The local chapter arranges informational meetings twice a year for people with pacemakers. I went there to listen and met some people that I chose to stay in closer contact with. We've become a bunch who meet and go out to eat now and then to talk about everything. For a time, I had a lot of existential questions. It's easier to exchange such thoughts with those who are like-minded and have been in the same situation as me. You have similar experiences, like in the beginning, when you worry about the heart attack, that it hurts, and the mental part."

In the UK, a national peer support network for people affected by a cardiac arrest was started in 2015 by Paul Swindell, a survivor himself. He experienced that there

were shortcomings in the follow-up care after cardiac arrest and that many needed to talk to others who'd been in the same situation. The Sudden Cardiac Arrest UK network today offers, among other things, a website, a Facebook group, a podcast, and an expansive group of members who can offer information and support to those who need it. More information is available at www.suddencardiacarrestuk.org. Along with occupational therapist Donna Malley, the network has developed informational material about fatigue. The material is translated into Swedish on the SRC's website hlr.nu.

www.hlr.nu/vard-efter-hjartstopp/





Tips and advice from experts, survivors, and others affected

Routines, structure and finding a good circadian rhythm will help your recovery. Sleep is important for you to function optimally, as will eating regularly and nutritiously. Start taking an active part in daily life as soon as you can, with all that entails, cooking, washing dishes, shopping, cleaning, paying bills and so on. Alternate activity with rest. Divide the activities and take regular breaks for resting. Rest is for you to be able to be active. Try to plan well in advance and choose the things that are most important to do. Learn to prioritize. Be sure to do something fun every day.

Physical activity is important and beneficial. For the first two or three weeks, maintain a walking regimen. It doesn't matter if you become short of breath, just take a break, listen to your body, and stop when it says no. Feel

free to contact a physiotherapist for exercise advice and an idea of what you can do.

It's normal to feel tired. The brain needs time to recover. The balance between activity and rest is important. Rest does not have to mean sleeping in the middle of the day, although many may need this for a while. Rest can also be taking a walk, listening to music, or performing some relaxation exercises. The most important thing is that the individual does take some rest.

It's normal to be anxious and depressed for a while. Stress reactions to what has happened can manifest as nightmares, or through avoiding things that remind you of what you've been through. Ask for help and support from those around you, and if that doesn't work, seek professional help. Talk therapy is available, for example, in primary



Useful links for more information

Swedish Resuscitation Council

www.hlr.nu

www.hlr.nu/vard-efter-hjartstopp/

Swedish Heart and Lung Association

www.hjart-lung.se

www.hjart-lung.se/natverket-for-overlevare/

Other resources

shlr.registercentrum.se/

www.hjartstartarregistret.se

www.suddencardiacarrestuk.org/

www.icuregswe.org/patient-och-narstaende/

www.1177.se/

www.hjart-lungfonden.se/

neuro.se/symtom/hjaerntroetthet/

care and via 1177. Loved ones may also need the same support.

The inability to concentrate and the exhaustion can make it more difficult to turn off irrelevant information, for example, if several people are talking at the same time. It's important to inform those in your surroundings about this and to take regular breaks.

Initially, you can plan for how long you will participate in social activities, or find out whether it is possible to leave and rest. It can also be good to sit with your back against an open space with many people, such as in a restaurant. When returning to work, it may be inappropriate to work in an office with an open floor design. A solution can be to gain access to your own room or to work from home part-time. Many people find that noise-cancelling headphones are a good tool.

If you experience memory problems, it's important to learn to use it in the best way to make daily work for you as best as possible.

An occupational therapist or neuropsychologist can give further advice, but some examples of strategies for memory problems can be to always do things the same way, to use a calendar regularly, to use checklists to help you remember to do things, to write memoirs, memos, or take photos with your mobile phone to make it easier to keep track of or retrieve information. Mobile phones can also be used to set alarms as reminders for things that are important to remember, such as important conversations or taking medication.

If you do not feel well without knowing why: Dare to ask for help!



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