Life after cardiac arrest

Information for survivors and their loved ones

Published in 2021 and revised 2026 by the Swedish Resuscitation Council and the Swedish Heart and Lung Association.

Foreword

To those who have experienced a cardiac arrest

This material provides information and advice for people who have experienced a cardiac arrest. Experiencing a cardiac arrest is a life-altering event, whether you are a survivor or a loved one. Research shows that most people recover well, but returning to everyday life after a cardiac arrest can vary greatly. It is natural to feel overwhelmed, confused, and to have many questions. The information provided here will not answer all of your questions, but aims to give an idea of what may happen, and directions on where to find more help. The information given is broadly general in nature, and local differences may exist, for example in the care available after a cardiac arrest. The content is primarily intended to supporting adult survivors and their loved ones, although parts of the content may also be relevant for affected children and their loved ones.

In addition to describing the different stages of care and recovery, the material also includes quotations in which survivors and family members share their personal experiences and reactions. It can be helpful to recognize aspects of your own experience in the experiences of others.

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

A special thank you to the survivors and loved ones who shared their stories and experiences.

More in-depth information on care guidelines can be found on the SRC's website:
www.hlr.nu/vard-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 and revised 2026 by the Swedish Resuscitation Council and the Swedish Heart and Lung Association.
Photo: Private, iStock Photo, Shutterstock

Contents:

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 suffered a cardiac arrest during a cycling holiday on Bornholm. Thanks to my wife, Annmargreth, who immediately started CPR, and to Ole, Erik, and Sennait, who came to help, I am alive today and I feel good. I am incredibly grateful for the actions of those who saved my life, and I often think about how fortunate I was. Their quick 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, has made it possible for me to continue living. 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 full-time work and can exercise more today than I could before my cardiac arrest.

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:

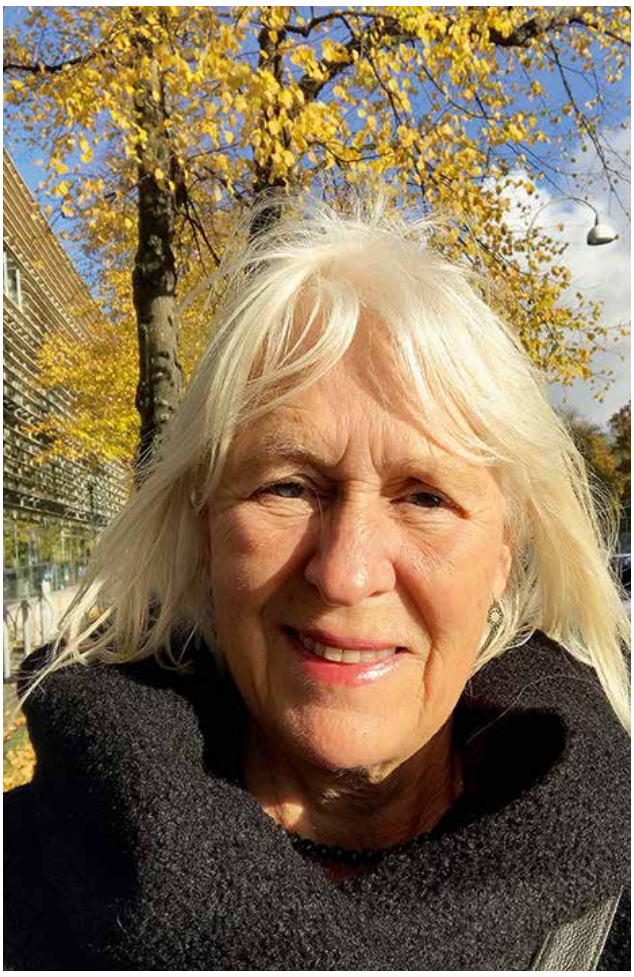
When Stefan collapsed over his bicycle, I immediately realized that something serious had happened and I began CPR. For 20 minutes, we kept Stefan's heart beating until the ambulance arrived. When it was time to transport him to Copenhagen by ambulance helicopter, I began documenting. I photographed a lot over the next few days so that I could show the pictures to Stefan when he woke up.

I was by his side almost all the time during the first two months. In the beginning, it was very important for me to accompany him to all his healthcare appointments.

When Stefan became healthier and could return to work, I was able to start letting go.

Then it was my turn to experience health problems of my own, in the form of widespread skin problems, eczema and itching. The problems persisted for almost a year."

Survivors and loved ones who share their stories:



"After almost 24 hours in a coma, with my family not knowing whether I would survive or not, 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, with my family not knowing 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 severe 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.

Nowadays, I feel much better. It's been a challenge to deal with my difficulties and learn 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 when we, her parents, husband, and siblings found ourselves in a bubble, in a complete vacuum, in a small room for relatives at the intensive care ward.

We lived in complete uncertainty about whether she would survive or if she would suffer serious brain damage from the 15 minutes without oxygen during the cardiac arrest. 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 from 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 dedicated to saving lives in the event of sudden cardiac arrest in hospitals and in the community. The SRC's vision is that all citizens should be able to perform cardiopulmonary resuscitation (CPR), use a defibrillator, and provide first aid in cases of sudden cardiac arrest and other life-threatening situations. The ultimate goal is to ensure that survivors have the best possible conditions 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

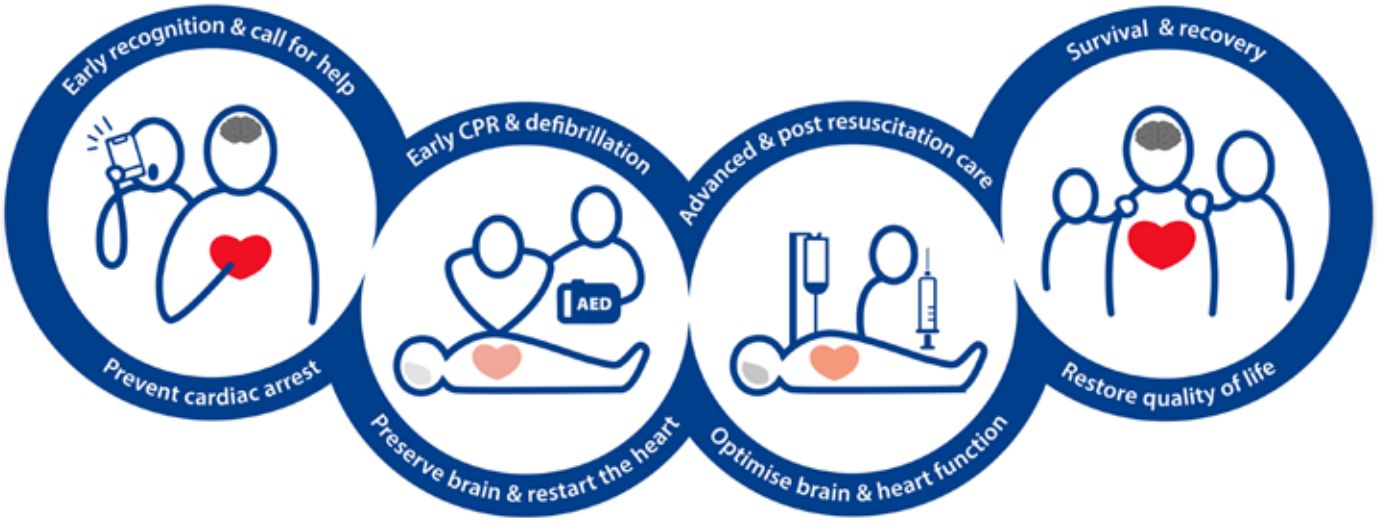
The Swedish Heart and Lung Association: "A strong voice for good care"

The Swedish Heart and Lung Association is a nationwide patient organization that works to ensure that all people with heart, vascular and lung diseases receive the best possible care and quality of life. This is achieved through information and education, advocacy towards politicians and decision-makers, collaboration with other stakeholders, support for patient-centered research, and customized lifestyle activities for members. At the heart of the organisation is the sense of community and support provided by local chapters across the country through meetings and activities.

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

- All people with cardiovascular and pulmonary disease should receive an early and accurate 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.
- Clear patient information, patient education, and greater patient involvement in care. The Swedish Heart and Lung Association is non-partisan and non-religious and is run by volunteers at national, regional, and local levels.

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



The Chain of Survival

Each year in Sweden, approximately 8,500 people suffer a sudden cardiac arrest, both in-hospital and out-of-hospital, for which cardiopulmonary resuscitation (CPR) is initiated. Of these, more than 1,500 people survive.

Cardiac arrest means that the heart suddenly stops pumping blood effectively. This can be caused by various heart rhythm disturbances, such as chaotic electrical activity in the heart's ventricles or a complete cessation of the heart's activity.

A cardiac arrest is a dramatic event, whether it occurs in a hospital, in the community, or at home. The chances of survival depend on a series of actions often described as links in a chain known as the "Chain of Survival":

8 500

people receive CPR every year after suffering a cardiac arrest.

- Early recognition and call for help to prevent cardiac arrest
- Early CPR and defibrillation to protect the brain and restart the heart
- Advanced life support (ALS) and post-cardiac arrest care to optimize brain and heart function
- Survival and recovery to restore quality of life

Time to CPR and defibrillation is crucial for survival. This brochure focuses on the fourth link, which includes aspects such as follow-up care and rehabilitation.

Early recognition and call for help to prevent cardiac arrest

Sudden chest pain or severe shortness of breath are common signs of myocardial infarction, which is the most common cause of cardiac arrest in adults. It is therefore important to call an ambulance immediately if a myocardial infarction is suspected.

When children suffer a cardiac arrest, it is often due to a lack of oxygen caused by factors such as a severe infection, drowning, or intoxication.

Early recognition of cardiac arrest and an early call to 112 are crucial to enable the rapid dispatch of an ambulance, the initiation of CPR, and early defibrillation. Emergency dispatch operators can provide instructions on how to perform CPR while waiting for an ambulance, rescue services, or other dispatched responders such as police officers and volunteer lifesavers to arrive.

Within healthcare settings, it is important to have systems in place to detect serious deterioration in patients at an early stage. This allows treatment to begin promptly and helps prevent cardiac arrest. When a cardiac arrest occurs in a hospital, an alert is usually activated via an emergency call button that notifies a medical emergency team.

Early CPR and defibrillation to protect the brain and restart the heart

If a person suffers a cardiac arrest, CPR should be initiated immediately. CPR increases the chance of survival two- to threefold compared with situations where no CPR is started before the ambulance arrives.

CPR consists of chest compressions and rescue breaths, which help oxygenate and circulate the blood to the body's organs while waiting for a defibrillator or other treatment. According to current guidelines, CPR for an adult involves a combination of 30 chest compressions followed by 2 rescue breaths.

Emergency dispatch operators can assist untrained rescuers by providing instructions over the phone. In such cases, chest-compression-only CPR is recommended. In hospitals and ambulance services, a device that delivers mechanical chest compressions is sometimes used.

When performing CPR on a child, the rescuer begins with 5 rescue breaths, followed by a cycle of 15 chest compressions and 2 rescue breaths.

Defibrillation involves delivering an electrical shock to the heart using a defibrillator (AED) with adhesive electrode pads placed on the chest. The shock can interrupt chaotic electrical activity (ventricular fibrillation) and help restart the heart. Defibrillation within three minutes can increase the chance of survival to as much as 70%.

Advanced life support (ALS) and post-cardiac arrest care to optimize brain and heart function

Important measures taken in the ambulance and in hospital, in addition to CPR and defibrillation, include providing more advanced treatment (Advanced Life Support, ALS), which involves airway management, medication administration, and efforts to identify and treat the underlying cause of the cardiac arrest.

After a cardiac arrest, there is usually a period of unconsciousness of varying duration. Post-cardiac arrest care therefore most often takes place in an Intensive Care Unit (ICU), where advanced equipment is used to monitor the heart and other organs of the body. A nurse or nursing assistant is always present in the patient's room to detect changes in the patient's condition and respond immediately to any complications.

Depending on the course of events and the cause of the cardiac arrest, ICU care is tailored to the patient's individual needs. Treatment may include mechanical ventilation to support breathing and temperature management to prevent fever.

If there is reason to suspect that a myocardial infarction (a blockage in one of the heart's coronary arteries) caused the cardiac arrest, a coronary angiography is often performed. If necessary, this may be followed by percutaneous coronary intervention (PCI), commonly known as balloon angioplasty, to restore blood flow to the heart.

This is a very difficult time for family members and loved ones. There is often a great deal of uncertainty, many questions, and few answers. There is a risk of developing a brain injury as a result of the lack of oxygen that can occur during a cardiac arrest.

Once heart function has been stabilized, assessing the extent of any potential brain injury becomes the most important consideration. During the first few days after a cardiac arrest, doctors are generally unable to provide a reliable prognosis. Information provided to loved ones becomes more detailed, and the prognosis more certain, as more time passes after the event.

A more reliable assessment can usually be made three to four days after the cardiac arrest, although in some cases more time may be needed. To evaluate the extent of brain injury, various tests may be performed, including examinations of the brain's electrical activity (EEG), computed tomography (CT) scans, magnetic resonance imaging (MRI) of the brain, and blood tests that measure different biomarkers of brain injury.

During the ICU stay, patients who show signs of awakening may frequently drift in and out of a drowsy or semi-conscious state. In the early stages, many patients experience confusion, but this is usually temporary. Over time, they often become increasingly aware of time and place and gradually begin to recognize family members and loved ones.

Patients who awaken while in the ICU may not necessarily remember this period later on. Instead, conscious awareness often returns more clearly after transfer to a regular hospital ward. Some patients describe their time in the ICU as a "black hole," while many retain only vague memories of the experience.

The length of stay in the ICU varies. Most patients spend two to three days there, while some remain for several weeks. Keeping a diary of the patient's stay in the ICU and on the hospital ward can be very helpful later when filling gaps in memory. Events and details that may seem insignificant at the time can become very meaningful during the recovery process.

The diary is usually written by ICU staff, but family members and loved ones may also be encouraged to contribute. The diary may also include photographs taken during the hospital stay. Such a diary can help patients better understand what happened during the period when they were unconscious or have limited recollection of it, and it can be a valuable tool in supporting both emotional recovery and rehabilitation.

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

Family members and loved ones play an important role in patient care by being present and providing support. Children are often welcome to visit while the patient is being treated in the ICU. Studies have shown that children generally cope well with visiting a critically ill relative. For this reason, children should be given the opportunity to visit their loved one and to ask healthcare professionals any questions they may have. Such visits can help children better understand the situation, reduce anxiety, and help them to feel included during a difficult and uncertain time.

"It was agonizing to just sit and wait. I shut everything else out and prepared myself to stay focused if or when something new happened. Holding my wife's hand was a way of transferring my energy to her."

"I didn't know whether I was going to become a widow or whether I would get my husband back, and, if so, in what condition. What would happen to our whole family? It was an incredibly anxious time not knowing what the outcome would be. The doctors found it difficult to say anything about the prognosis, but otherwise they shared all the information they could."

"At first, my thoughts kept circling around the fact that he was all I had. He had just graduated from high school. How could this happen? The emergency physician said, 'He's going to make it through this.' At the same time, I knew that he couldn't really know for certain either. In the ICU, they said, 'He has very good chances of recovering from what has happened, but we cannot yet know whether his brain has suffered any injury.' My thoughts

then started spinning in a different direction: what if he has brain damage?"

On the hospital ward

For many patients, being transferred to a hospital ward is a sign of recovery and progress. However, some may also experience anxiety and uncertainty about leaving the safe and closely monitored environment of the ICU.

On the ward, physical improvements often occur rapidly. At the same time, many patients experience short-term memory problems. This may be a sign that the brain has been affected by the cardiac arrest, but at this stage it can also be caused by a variety of other factors, such as medication side effects, emotional stress, lack of sleep, fatigue, or pain. It is important to remember that patients often need rest and regular breaks, and that information may need to be repeated several times or written down.

Most patients are also unable to remember what happened to them. Not being able to recall the event itself, or even the time leading up to it, can be distressing. In the quotations below, family members share some of their experiences.

"The improvements happened very quickly. My wife was soon up and walking around, but her short-term memory wasn't really functioning properly. She kept asking the same questions over and over again. At first, she didn't even know where she was."

"My husband remembers his time in the cardiac ward as a confusing and overwhelming period. He tested the boundaries and wanted to leave the ward without monitoring. Later, however, he felt that this was too unsettling and quickly returned."

It is natural for patients and their families to begin thinking about the future and what life will be like moving forward. A great deal of information is often needed to understand and cope with what has happened. Further investigations into what triggered the cardiac arrest, the need for medication, and various types of risk assessments are carried out either during the hospital stay or after discharge. Depending on the cause of the cardiac arrest, some patients may also receive an implantable cardioverter-defibrillator (ICD), a device that can detect and treat potentially life-threatening heart rhythm disturbances.

Survival and recovery to restore quality of life

Before discharge, an assessment is recommended to determine whether there are any signs of physical or non-physical difficulties (for example, emotional reactions) that could affect daily life. The results of this assessment can serve as the basis for planning any ongoing rehabilitation needs. Post-cardiac arrest care should strive to be person-centred, meaning that it is based on the patient's experiences, personal account, and healthcare needs, and is planned together with the patient and their family members or loved ones.

As part of the discharge process, discussions should take place regarding issues such as:

Sick leave and return to work, medications, driving restrictions and recommendations, ongoing follow-up care, contact information for healthcare providers, planned treatments and healthcare interventions.

It is beneficial for a family member or loved one to participate in these discussions, as there can be a large amount of information to absorb. The information should also be provided in written form.

The Swedish CPR Council's guidelines for follow-up after cardiac arrest recommend that, whenever possible, patients should be offered a designated contact person at the time of discharge. However, the availability of such support varies depending on local healthcare resources and circumstances. The Swedish CPR Council has published a short informational brochure that can be used at discharge. Both the guidelines and the brochure can be downloaded from hlr.nu.

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

Follow-up and rehabilitation

A range of healthcare professionals and areas of expertise are involved in the follow-up care and rehabilitation of cardiac arrest survivors. Physicians and nurses specializing in cardiology, neurology/rehabilitation medicine, and intensive care medicine are often involved in patient care. Other professionals, such as occupational therapists, dietitians, physiotherapists, neuropsychologists, psychologists, and social workers, may also be involved when needed.

Services may differ across regions, but it is important to establish local referral pathways and structured collaboration among care providers involved in follow-up. All patients should be offered a follow-up appointment at the hospital within one to three months after discharge. Such follow-up is usually provided through a cardiology clinic and/or a post-ICU clinic. For children who have experienced a cardiac arrest, follow-up care for both the child and their family should initially be coordinated through specialist healthcare services.

During a structured follow-up assessment, in accordance with the Swedish CPR Council's guidelines, healthcare professionals evaluate whether the patient and their family have received sufficient information about the cause of the cardiac arrest, the sequence of events surrounding the incident, sick leave and return to work, driving restrictions and recommendations, and other relevant aspects of recovery and ongoing care.

The assessment also explores whether there are any persistent difficulties related to the cardiac arrest, such as physical fatigue, mental fatigue (cognitive exhaustion), pain, physical limitations, cognitive difficulties (problems with thinking, memory, attention, or concentration), emotional or psychological challenges. If additional support needs are identified, it is important that the follow-up process leads to a clear plan for further evaluation and, if appropriate, rehabilitation.

Collaboration with primary care services is essential, as much of the ongoing follow-up is likely to take place there. Patients who have received an ICD are generally scheduled for regular check-ups at the hospital's cardiology clinic.

The nature of rehabilitation following a cardiac arrest depends largely on the underlying cause of the arrest and any consequences resulting from the event. Because myocardial infarction and other cardiovascular diseases are responsible for most cases of cardiac arrest, an important aspect of post-cardiac arrest care is reducing the risk of future heart problems, known as secondary prevention. This may include medications to lower blood pressure and cholesterol levels, support for smoking cessation, stress management strategies, physical activity and exercise programs.

Some cardiac arrest survivors are offered the opportunity to participate in specialized cardiac rehabilitation exercise groups, led by a physiotherapist. Being able to exercise and exert oneself in a safe and supervised environment can facilitate recovery. Many hospitals also offer cardiac education programs consisting of a series of lectures delivered by different healthcare professionals. These programs may be provided either in person or online.

If cognitive difficulties are present, such as, problems with memory, concentration, or planning abilities, further evaluation by an occupational therapist or neuropsychologist may be recommended. It is important to understand the underlying causes of these difficulties. Some problems may be related to brain injury sustained during the cardiac arrest, while others may result from factors such as physical fatigue, mental fatigue (brain fatigue), poor sleep, emotional or psychological challenges. Various strategies and assistive tools can help make everyday life easier. These may include memory aids such as alarms and reminders, calendars, and to-do lists.

Support may also involve adapting daily routines and finding new ways of carrying out everyday activities. For the small number of survivors who have sustained a severe brain injury, treatment and support from a specialized rehabilitation unit and/or a cognitive medicine service may be required.

Because emotional reactions are common after a cardiac arrest, it is appropriate to offer both patients and their family members contact with a social worker (counsellor) or psychologist, who can assess the need for additional support and interventions.

Back to daily life

Experiencing a cardiac arrest is a life-changing and overwhelming event, whether you are the survivor or a family member. People respond in different ways. Most survivors recover well and are able to live a normal life, but recovery often takes time. Difficulties with memory, concentration, fatigue, and emotional reactions are relatively common, especially in the early stages. Recovery varies from person to person. The greatest improvement typically occurs during the first few months, but progress often continues for a long time.

It is important for family members to be involved in follow-up care and rehabilitation. Experiencing a cardiac arrest yourself, or having a family member experiencing one, can trigger a crisis reaction, which is completely normal. People may react with varying degrees of intensity to similar events and situations, but help is available. More information can be found through Sweden's national healthcare guide (1177), your healthcare clinic, or your primary care provider.

www.1177.se/Vastra-Gotaland/liv--halsa/psykisk-halsa/att-hamna-i-kris/

If there are young children in a family where someone has suffered a cardiac arrest, it is important to inform the school or preschool about what has happened so that staff can understand the situation and provide the best possible support for the child. Traumatic experiences can affect children for a long time and may lead to new behaviours that those around them need to understand and manage. For older children as well, it is important to continue doing things they enjoy and that promote well-being, such as spending time with friends. Attending school provides routines, a sense of security, and a break from difficult thoughts. There, they have friends and caring adults around them. It is also important to talk to someone they trust, such as a parent, a teacher, or a healthcare professional, and not try to carry the burden of the experience alone.

During the initial period after the event, some patients and family members describe feelings of uncertainty and insecurity. Over time, however, improvements in various aspects of life often contribute to a growing sense of safety and confidence. In the quotations below, survivors and their family members share some of these experiences and emotions.

"At first, I was worried. I couldn't sleep at night; I was afraid that my heart would stop when I fell asleep. But those feelings went away after the first two weeks."

"It felt very unsettling. Just the feeling that all the monitoring was suddenly gone. What would we do if something happened? Everyone in the family was afraid that something would happen, that his heart would stop again. They had told us at the hospital that the risk was minimal. But when my husband lay down on the couch to rest, one of the children was often nearby, checking that his chest was moving and that he was breathing."

"The doctors still do not know why I suffered a cardiac arrest, despite all the examinations. That is something I have to learn to live with."

"At first, I didn't dare go alone on my usual exercise trail. Since I wasn't allowed to drive, I took the bus into town instead. There, I would walk around where there were other people in case something happened. A week later, I had grown tired of that and went back to the exercise trail, equipped with walking poles, my mobile phone, and nitrospray for my daily walks."

"An ICD can provide a sense of security for both the patient and their loved ones. For some patients, including myself, it is also a constant reminder of what happened, a source of gratitude for being alive, but also of sadness that I need an ICD in the first place."

The appropriate time to return to work depends on the type of job, the pace of recovery, and any lasting effects of the cardiac arrest. This assessment must be tailored to the individual's specific needs. Returning to work should be a gradual process. Initially, it may be beneficial to include a rest day during the workweek. However, this should be planned in consultation with the Swedish Social Insurance Agency (Försäkringskassan).

In some cases, Försäkringskassan may arrange a so-called coordination meeting before a person returns to work. The purpose of this meeting is to plan the return-to-work process in the best possible way, based on the individual's circumstances, and to establish an ongoing rehabilitation plan. Such a meeting may include the affected individual, a family member or loved one, the employer, the physician responsible for the sick leave certification, and a representative from Försäkringskassan. Other healthcare professionals, such as an occupational therapist, may also participate. Every primary healthcare center should have a rehabilitation coordinator who can provide additional support.

It is common to be advised not to drive for a period of time after a cardiac arrest. This is not the same as having one's driver's license revoked, but the recommendation should be followed. The regulations governing license suspension for medical reasons are set out in the Swedish Transport Agency's (Transportstyrelsen) regulations. The decision is made by a physician, most often a cardiologist. The duration of any driving restriction depends on the individual's medical condition.

When driving is resumed, it is advisable to proceed cautiously at first, for example, by avoiding long journeys without breaks and by paying attention to the effects of fatigue. If the individual works as a professional driver, there may be additional regulations and requirements that need to be considered.

"Today, I believe it was the right decision not to be allowed to drive immediately after going through such a big dizzying event. It takes time for the brain to get back up to speed. 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

Research examining health and quality of life among people who have survived a cardiac arrest shows that most survivors rate their overall health and quality of life as good six months after the event, with levels comparable to those of the general Swedish population.

Some survivors report that they appreciate life more, prioritize what truly matters, experience less stress, and feel that they have been given a second chance.

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

"Strictly speaking, I shouldn't be here today. Since I am, it means there is something I need to make the most of. It's not something I can afford to waste."

Although most people rate their health and quality of life as good, experiences of life after cardiac arrest vary greatly from person to person. Having a "near-death experience" such as a cardiac arrest can also increase awareness of one's own vulnerability. Some survivors describe the first period after the event as a search for meaning and a sense of control.

The most commonly reported health problems among cardiac arrest survivors are emotional reactions, cognitive difficulties, sleeping problems, and fatigue. Fatigue is defined as "a feeling of exhaustion that appears disproportionate to the individual's level of activity." During the early stages of recovery, many people also experience chest pain caused by CPR. This pain usually decreases and disappears after a few weeks.

Common emotional reactions may include worry or anxiety, low mood, and stress-related symptoms. Some people experience panic attacks, which can be very distressing and may cause sudden symptoms such as heart palpitations, tingling sensations throughout the body, shortness of breath, dizziness, nausea, and cold sweats. The physical symptoms of panic attacks can resemble those experienced during a myocardial infarction. Although frightening and highly unpleasant, they are harmless. If symptoms are severe enough to lead someone to seek hospital care, they usually decrease once tests have been performed showing that there is nothing wrong with the heart.

If panic attacks recur, the condition can be treated with supportive counselling, medication, or cognitive behavioural therapy (CBT). CBT can be used to treat stress-related problems, sleep difficulties, anxiety, panic disorder, and low mood or depression.

"It felt almost exactly the same, except that everything never went black. I never lost consciousness. I had heart palpitations, cold sweats, shortness of breath, pressure in my chest, and a feeling of anxiety. It never occurred to me that it could be my mind playing tricks on me. I went to the emergency department and was told a few hours later that everything was fine."

"She suffered from severe dizziness, probably related to anxiety. One thing led to another. She couldn't run errands, go shopping, or even visit a grocery store because of the dizziness and anxiety."

"After waiting several months for CBT treatment, I bought a book on self-help CBT. I trained myself to interrupt the panic attacks when they occurred and to understand that the attacks were essentially a trick of the mind. When I felt an attack coming on, I would somehow shake it off by redirecting my thoughts. After some time, my problems disappeared."

Cognitive (thinking-related) difficulties may be a consequence of a brain injury, but they can also be related to other factors such as poor sleep, fatigue, or depression. The most common cognitive difficulties involve reduced memory, concentration, processing speed, and planning ability. Many people also experience mental fatigue and a lack of energy. This mental fatigue may be related to a brain injury, meaning that the brain requires more effort and energy to process information.

A person with cognitive difficulties and/or mental fatigue often becomes tired more easily than before and may be more affected by insufficient sleep, exertion, stress, or low blood sugar. When the brain is exposed to too many impressions or stimuli, it may become overloaded and not function as it should. It is important to understand that mental fatigue does not necessarily indicate a brain injury, and that mental fatigue itself can lead to a feeling of cognitive impairment.

When we become tired, it is harder to concentrate, which in turn affects our memory. Therefore, minimizing the effects of fatigue is important for managing everyday »

life. The environment should be calm and well-structured, with opportunities for regular breaks that alternate periods of rest and activity. Rest enables many people to maintain a higher level of activity, and taking breaks before becoming overly fatigued can be important in reducing recovery time.

Attitudes and expectations from others, as well as from oneself, can create demands that are difficult to manage. It is important to prioritize activities and return to them gradually. These difficulties often become most noticeable when a person returns to work. Many survivors tend to push themselves too hard. Part of the continued improvement may come from learning how to manage problems related to low energy levels, which generally improve over time.

Together with occupational therapist Donna Malley, the UK peer support network has developed educational material about fatigue. This resource has been translated into Swedish and is available on the Swedish Resuscitation Council's website (hlr.nu).

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

"I realized fairly quickly that things were not back to normal. My memory was unbelievably poor. I would forget things, such as going outside to take out the trash. I would find myself standing there with the garbage bag in my hand, wondering what I was supposed to do. It was embarrassing. I didn't want to tell anyone about my problems."

"I do have some memory difficulties, but they do not significantly affect my everyday life."

"I can do exactly the same things as I did before, but now I have

to do them one at a time. I cannot juggle so many balls at once anymore."

"I kept a diary throughout the first year as a memory aid. My memory was so poor that I could not remember what I had done the day before or even two days earlier. Last week, or anything further back, felt as though it had never happened. The diary also helped me look back and see my progress and improvements. I would often turn back a month and read about how I had been feeling then, and almost every time I could see that things had improved, which gave me hope."

The need for follow-up care and/or rehabilitation varies from person to person. This depends partly on the extent of any brain injury, but also on individual factors. Some people are able to manage everyday life well despite memory problems, difficulties with concentration, and fatigue. Many experience no cognitive difficulties at all, while others are concerned that "something feels different." For those affected, it can be important to receive reassurance that the condition is not worsening and to know that support is available.

A person with cognitive difficulties must first become aware of what is no longer functioning as it did before. The next step is to learn compensatory strategies, that is, finding alternative ways to manage tasks and challenges. Occupational therapists are often key professionals in this process and are available, among other settings, within primary healthcare services.

There are also specialized rehabilitation clinics that offer comprehensive assessments of cognitive difficulties conducted by a multidisciplinary team. The results of these evaluations are used to develop an individualized rehabilitation plan. Interventions aimed at achieving the established goals may then include a more intensive period of training or longer-term support in various forms, for example to help manage daily life or facilitate a return to work.

One thing that many cardiac arrest survivors have in common is a profound sense of gratitude toward the person or people who saved their lives. Many feel motivated to spread awareness of the importance of CPR and to encourage as many people as possible to learn how to start resuscitation when it is suddenly needed.

"I decided to put what had happened behind me and move forward. Creating my own website is my way of helping others. I want to make my municipality heart-safe, and I have started a fundraising campaign to obtain automated external defibrillators (AEDs). My coworkers and friends have been trained in CPR, and today I write a blog about my life."

"Some time after the cardiac arrest, our daughter contacted the healthcare service to try to get in touch with the two volunteer responders who came to our home after receiving the emergency alert. The responders appreciated receiving feedback about the outcome, and their meeting with our daughter and her husband helped both them and the responders process what they had experienced."

Health and quality of life in family members and loved ones

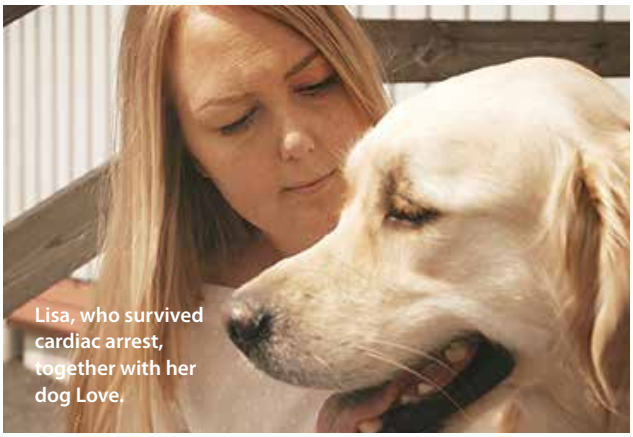
Being a family member or loved one of someone who has suffered a cardiac arrest can be extremely stressful, especially for those who were present when the cardiac arrest occurred and may even have performed life-saving treatment. The first days in the ICU following a cardiac arrest, as well as the period when the patient begins to regain consciousness, are often experienced by family members as uncertain and chaotic.

The role of family members during the recovery period can vary considerably. Many become an important source of support for the survivor. This may involve helping with practical aspects of daily life, such as providing assistance, guidance, reminders about important tasks, follow-up, or encouragement. It can also mean being available to listen, provide reassurance, and respond to a wide range of emotional reactions.

At the same time, family members often have their own trauma to cope with. Witnessing or being involved in a cardiac arrest, whether it affects a family member, a friend, or even a stranger, can evoke many emotions. Experiencing a cardiac arrest situation is frightening. Feelings of fear, confusion, and grief are common. Some people have difficulty sleeping or experience distressing flashbacks, while others feel almost nothing at all.

Many family members naturally hesitate to express their own emotions because they do not want to worry the survivor. As a result, their own needs are often placed second during the early stages of recovery, and their emotional reactions may not become apparent until much later.

The lives of the entire family are affected by such an event. Children and grandchildren may sometimes be overlooked, even though they, too, are coping with a crisis.



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

They may be struggling emotionally but may not want to show that they are having difficulties.

"You have to find ways to manage the worry you feel for the person affected, not only the fear of another cardiac arrest, but also concern about the sometimes subtle cognitive changes. I was offered counselling early on, but it was not until we had made it through the first six months that I was ready to accept it. Until then, there was simply so much practical stuff to deal with in order to make everyday life work."

"In our family, our six-year-old understood that dad was ill and in the hospital. When dad came home, everything seemed fine. Our son appeared to adapt to the situation quite easily. What affected him more was seeing how tired and exhausted his mother was. Other people had to step in to help and take care of him. Our daughter, who was 13, was there when it happened. She found it difficult to put her feelings into words and did not want to talk about it. Eventually, we took the initiative ourselves and contacted a child psychologist. They carried out an assessment about six months later. Looking back, I think it was a frightening experience for her, but perhaps also one that helped her grow. As she saw her father make progress and gradually become more like his old self again, things improved for her as well."

"Our three-year-old granddaughter carried fear and uncertainty for a very long time after witnessing her mother's cardiac arrest. She could not bear to be away from her mother for even a moment and wanted to follow her from room to room all day long."

"We have returned to our previous routines. We do everything we used to do without feeling limited in any way. We have gone back to playing golf, visited our summer cottage to pick cloudberries, and even taken a coach trip abroad."

Research shows that most family members and loved ones rate their overall health and quality of life as good six months after the event. However, emotional reactions, stress-related symptoms, and sleep problems appear to be at least as common among family members as among the person who survived the cardiac arrest. These reactions are particularly common among those who witnessed the cardiac arrest and performed CPR. For some family members, it can be helpful to talk to someone outside their circle of family and friends, such as a social worker, counsellor, or psychologist. Do not hesitate to ask healthcare professionals for help in finding the right support.

Network/Peer support

Experiencing a cardiac arrest or being diagnosed with a heart, vascular, or lung disease often serves as a reminder of the fragility of life. However, there are excellent opportunities to return to an active and fulfilling life. The Swedish Heart and Lung Association (Riksförbundet HjärtLung) exists to provide advice, support, and encouragement to those affected and their families.

Community

After a cardiac arrest, it is easy to feel isolated and alone. Yet a good quality of life is possible, even if that may be difficult to see at times. Returning to an active life takes time. It is often both easier and faster when you are surrounded by people who are in a similar situation.

Local branches of the Swedish Heart and Lung Association offer opportunities to make new lifelong friends. They organize activities, lectures, social gatherings, and opportunities to share knowledge, experiences, companionship, and enjoyment. Family members and loved ones also have an important place in the community and are always welcome to take part. Being able to meet others who are facing similar challenges can be an invaluable source of support.

Lifestyle

As a member of the Swedish Heart and Lung Association, you can receive support with lifestyle changes that promote better health, participate in themed events, and much more. The focus is on what health means to each individual and what each person can do to achieve the best possible well-being.

Lifestyle changes rarely happen overnight. Instead, they develop by establishing healthy habits and maintaining them over time. Often, one healthy habit leads to another: being physically active reduces sedentary behaviour, and eating nutritious, satisfying meals can lessen cravings for sugary foods. A healthy lifestyle is the result of many small everyday choices and can lead to an improved quality of life.

The Swedish Heart and Lung Association provides educational materials and exercise programs tailored for people who have experienced a cardiac arrest or who live with heart, vascular, or lung disease. Naturally, each individual decides which activities they wish to participate in, at what level, and how frequently. Family members and loved ones are warmly encouraged to join.

Programs are led by exercise and study-group leaders in local associations and may include activities such as medical yoga, group exercise classes, water aerobics, boules, Nordic walking, strength training, and lectures.

To increase awareness and knowledge about cardiac arrest, as well as heart, vascular, and lung diseases, local associations organize lectures on a variety of topics for both members and the general public. Speakers may include researchers, physicians, nurses, physiotherapists, and dietitians.

The Swedish Heart and Lung Association also offers digital lifestyle programs, which may include online meetings, exercise sessions, courses, lectures, and, importantly, opportunities for social connection through the internet. These online activities complement in-person gatherings and help make support more accessible to everyone.

Photo: MARIA CARLUND

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.

Network for cardiac arrest survivors and their loved ones

Connecting with others who have been through similar experiences can be an important source of support and a way to share knowledge and experiences. In the United Kingdom, a national peer support network for people affected by cardiac arrest was established in 2015 by Paul Swindell, himself a cardiac arrest survivor. He felt that there were gaps in the follow-up care available after cardiac arrest and recognized that many people needed opportunities to speak with others who had experienced similar situations. Today, Sudden Cardiac Arrest UK offers a range of resources, including a dedicated website, a Facebook support group, a podcast, and a large community of members who provide information, guidance, and support to those in need.

More information is available at: www.suddencardiacarrestuk.org

In Sweden, a national peer support network was also established in 2020 by a group of cardiac arrest survivors and their relatives, in collaboration with the SRC and the Swedish Heart and Lung Association. The network can be contacted through Facebook or email via the Swedish Heart and Lung Association.

The Swedish Heart and Lung Association also provides peer support networks through its local associations, offering opportunities for survivors and their loved ones to connect with others facing similar challenges.

"I received information about a patient support organization while I was in the hospital. The local association organizes information meetings twice a year for people with ICDs. I attended one of these meetings to listen and ended up meeting a few people with whom I chose to stay in closer contact. We have become a group that gets together from time to time to have a meal and talk about all sorts of things. For a period, I struggled with many existential questions. It is easier to share those kinds of thoughts with people who understand and have been through the same situation. We have similar experiences, such as the initial anxiety about receiving a shock from the ICD, concerns about pain, and the psychological aspects of living with what has happened."

Tips and advice from experts, survivors, and others affected

Establishing routines, structure, and a healthy daily rhythm can support your recovery. Sleep is important for optimal functioning, and regular, nutritious meals are equally important. Try to take an active role in everyday life again as soon as you feel able. This includes activities such as cooking, washing dishes, grocery shopping, cleaning, paying bills, and other daily tasks. Balance activity with rest. Break activities into smaller steps and schedule regular breaks. Rest is important because it allows you to remain active. Try to plan ahead, decide which tasks are most important, and learn to prioritize. Also, make sure to do something enjoyable every day.

Physical activity is beneficial and important for your recovery. During the first two to three weeks, it is recommended to keep activity at the level of walking. It is okay to become somewhat short of breath, just take a break, listen to your body, and stop when it signals that it has had enough. Consider consulting a physiotherapist for exercise advice and guidance regarding what level of activity is appropriate for you.

Feeling tired is completely normal. The brain needs time to recover. What matters most is maintaining the right balance between activity and rest. Rest does not necessarily mean sleeping during the day, although many people may need this for a period of time. Rest can also involve taking a walk, listening to music, or practicing relaxation exercises. The most important thing is that the activity feels restful to you.

It is also common to feel worried, anxious, or low in mood for a period of time. Stress reactions related to what has happened may appear as nightmares or a tendency to avoid situations that remind you of the event. Seek support from the people around you, and if that is not enough, seek professional help. Supportive counselling is available through primary healthcare services and

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/

through Sweden's healthcare information service, 1177. Family members and loved ones may also benefit from the same type of support.

Difficulties with concentration and increased mental fatigue can make it harder to filter out irrelevant information, for example, when several people are talking at the same time.

It may be important to inform those around you about these challenges and to take regular breaks. At first, it can be helpful to plan in advance how long you will participate in social activities or to check whether there is an opportunity to step away and rest if needed.

It may also help to sit with your back toward open areas in environments such as restaurants, reducing the number of visual distractions. When returning to work, an open-plan office may not be the most suitable environment. Possible solutions include having access to a private office or working from home for part of the time. Many people find noise-cancelling headphones to be a helpful aid.

If you feel that your memory is not as good as it used to be, it is important to learn strategies that help you make the best use of it, enabling you to manage everyday life as effectively as possible. An occupational therapist or neuropsychologist can provide additional guidance, but examples of useful memory strategies include performing tasks in the same way each time, using a calendar regularly, using checklists to remember important tasks, writing notes and reminders, using sticky notes, taking photos with a mobile phone to help keep track of information or to aid recall later. A mobile phone can also be used to set alarms and reminders for important tasks, such as making a phone call or taking medication.

If you do not feel well and do not know why, do not hesitate to ask for help!

HLR rådet
SVENSKA RÅDET FÖR HJÄRT- LUNGRÄDDNING

Riksförbundet HjärtLung

LIFE AFTER CARDIAC ARREST
Published in 2021 and revised 2026 by the Swedish Resuscitation Council and the Swedish Heart and Lung Association.