I CARE

So, your loved one has had a cardiac arrest

Sudden Cardiac Arrest UK

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1 INTRODUCTION

A cardiac arrest is when the heart stops suddenly, and without resuscitation and expert care the patient will not survive. Although cardiac arrest is often caused by a heart attack, they are not the same. Suffering a cardiac arrest is not uncommon. Once admitted to hospital the likelihood of a good outcome improves dramatically, with a survival rate of around 50%.

For those that do survive this event, confusion is fairly common in the early stages of 'waking up' there will also be concerns about further episodes, and questions surrounding a long and sometimes complex recovery.

For the family and friends of the patient, there is significant distress. They are left with uncertainty about whether their loved one will survive. They may have witnessed resuscitation or attempted it themselves – both of which can be very distressing.

In this leaflet we will aim to explore:

- Questions and concerns by those whose loved one has recently had a cardiac arrest
- Some of the processes that are likely to occur during a hospital admission
- Some of the long-term difficulties that may be faced by cardiac arrest survivors and how this may impact those close to them

We aim to provide accessible information on the processes and experiences. However, not everyone will have the same experiences. If this leaflet does not resonate with you, if you find reading it is too upsetting or if you have further questions then we have a section talking about other available support.

In the regrettable event that your loved one does not survive, you may want to seek bereavement support so please see the resources listed at the end of this leaflet or on the Sudden Cardiac Arrest UK website.

Sudden Cardiac Arrest UK provides peer support and resources for survivors and those affected by the survivor's event. Dr Michael Smith, Consultant Cardiologist Dr Thomas Keeble and Clinical Psychologist Dr Marco Mion have kindly created this document for distribution to family and friends soon after the patient is admitted to the hospital.

2 RESUSCITATION RESPONSE

Witnessing or participating in a resuscitation event can be deeply troubling, especially if the person being resuscitated is a loved one.

You may experience distressing memories of the event, and these may persist for a significant time. It is also common to have feelings of doubt. 'Did I do the right thing?', 'Could I have stopped this from happening?'. You may experience periods where these feelings improve and then worsen. This is normal, and you should allow yourself to feel like this, there's nothing 'wrong with you' for feeling this way.

Unfortunately, there is currently limited support aimed at those responding to or witnessing a resuscitation. However, we also have resources specifically focussed on this area, please ask for them or read online at our website.

For some, it will help to simply be aware that this distress is a very normal response. Others may wish to discuss their concerns with someone, be it a layperson who has had a similar experience, a medical professional or even a counsellor.

For those wishing to interact with others who have been party to a resuscitation, you can join the group Chain of Survival UK. If you are looking for professional support, read the 'seeking professional support' section later in this leaflet.

"Did I do the right thing?"

"Could I have stopped this from happening?"

3 EARLY STAGES

During a cardiac arrest, there is no blood flowing through the body; if not treated quickly this can cause widespread injury to organs with the brain being at most risk.

People who have been resuscitated from a cardiac arrest will therefore usually be placed in a medically induced coma to minimise injury to the brain and at this time will also have their breathing supported with a ventilator.

Although this is very important to maximise the chances of recovery, it also means that in the first 72 hours it is often too soon to tell the extent of any brain injury and consequently it is difficult to know whether your loved one will survive or not.

During the initial days after the event, you may see several tests being carried out which will help the medical team understand the presence and extent of any brain injury. This can include a physical examination where they will assess the reflexes in the limbs and the size and response of the pupils, regular blood tests, and imaging of the brain with a computed tomography (CT) scan or magnetic resonance imaging (MRI). In some patients where the results are inconclusive, this initial stage can last up to and over a week.

4 IN-HOSPITAL RECOVERY

Cardiac arrest and intensive care unit (ICU) admission both cause significant physical and psychological stress.

It is common for patients to become disoriented whilst being treated in the ICU and this can lead to patients becoming agitated and aggressive. This is referred to as 'delirium' and will normally pass with time. The presence of loved ones can help to reorientate patients experiencing delirium. More information and support on the management of patients in ICU can be found via the charity ICUsteps.

Repetitiveness and confusion can be common and quite disturbing for you in the very early stages but they tend to resolve quickly. If these symptoms are being experienced by your loved one then the clinical team should be informed. If they occur regularly then there may be ways in which these symptoms can be supported although it is not always possible to stop them entirely.

Some of the other symptoms experienced in this phase may result from the physical and psychological trauma of the ICU admission.

When patients have a breathing tube placed they may sustain some injuries to their throat. This can lead to having difficulty with speaking and swallowing after they have been woken up from their medically induced coma. This is usually temporary but if this is not the case you may want to check if the hospital uses any tools such as RITA or the myICUvoice app which can help patients with communication.

Once a patient is medically stable and is being cared for on a normal hospital ward, there are likely to be several ongoing issues. The most common complaints reported by patients in this period are chest pain, fatigue and memory loss.

Cardiac arrest survivors often report that their memory is not as good as it was and this can be for many reasons. This will often improve with time but it can be useful to use a patient diary or notebook to aid the patient's memory. This can also be beneficial in the long term as it can show their progress.

5 IN-HOSPITAL INVESTIGATIONS

During the recovery phase, there are likely to be investigations performed to determine the cause of the cardiac arrest.

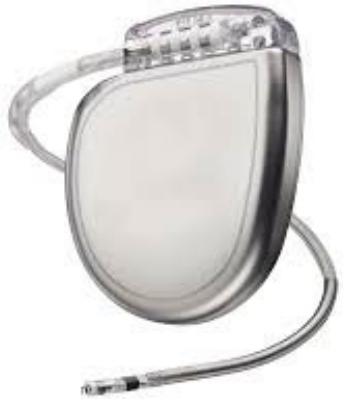
The most common cause of cardiac arrest is coronary heart disease. This is where there is a blockage in the arteries that feed the heart and is often called a 'heart attack' or myocardial infarction (MI). The best way to investigate this is with a coronary angiogram. This is done in a 'cardiac catheter lab' (Cathlab) and a wire is placed into the wrist or groin. This is then fed to the heart and a dye is injected into the arteries around the heart to see if there are any blockages. If any blockages are found, then a stent may be placed to reopen these.

A cardiac arrest can be caused by abnormal heart structure and function. Similarly, a cardiac arrest itself may cause damage and abnormalities in the heart. This is usually identified with an echocardiogram, which is a scan of the heart where some jelly and a probe is placed on the chest (like a pregnancy scan). If this does not provide sufficient detail, then a cardiac MRI scan may be desired.

In some cases, there may be suspicions that there is a genetic component to the cause of the cardiac arrest. If this is confirmed then the medical team may discuss whether it is required to perform genetic testing on other members of the family to determine whether they are at risk. These instances are relatively rare and more information can be provided by the treating team if it is needed.

Depending on the cause of the cardiac arrest, there are also a variety of treatments that may be given. Many people will be placed on new medications. For some this can cause distress as they have felt that they are a 'fit and well' person and having to take regular medication can make them feel that they are 'sick'. The benefits and drawbacks of any medications are best discussed with the medical team.

If the cause of the cardiac arrest was a heart rhythm problem or if the cause is not identified (idiopathic), then a pacemaker or implantable cardioverter defibrillator (ICD or S-ICD) may be fitted. This procedure is also performed in a Cathlab and involves placing a small box just under the skin, usually on the left side of the chest or abdomen. Wires go from the box to the heart to fulfil two main functions; effective pacing of the heart and correction of any abnormal heart rhythms (shock therapy). An ICD can usually do both, a pacemaker just pacing and an S-ICD just shock therapy, although this may vary per device. Some devices also have a separate remote monitor or phone app that communicates with the hospital providing added peace of mind.



After a sudden cardiac arrest most patients recover well, however, many will also report some ongoing symptoms (sequelae). One of the most common persistent symptoms is chest pain. This may be because of rib or cartilage damage due to CPR or from any procedures carried out. Usually, this will ease with time but the management of this pain can be complex as many patients wish to avoid the long-term use of opioid pain medications.

Other common sequelae are fatigue, lapses of memory, difficulty concentrating, emotional swings, personality changes, mental health challenges, issues with sleep, speech and language (aphasia) and brain fog. These can often be subtle and difficult to detect from the outside, particularly in those who were functioning at a high level before their cardiac arrest. This may lead to issues with returning to work and everyday activities such as driving. Most people find that these issues get a lot better in the first few months; however, if they persist you should consult their GP as further investigations and treatment may be necessary.

A hurdle that is reported by many is the short-term change in dynamics in the home environment. Given the symptoms previously mentioned, many people must change the tasks which they are completing day to day. This can include a temporary loss of ability to exercise, and some restrictions on their independence, including medical restrictions on driving.

Following a cardiac arrest, there will be a period where survivors are unable to drive, but the length of this varies depending on the cause of the cardiac arrest, the medical care received and any ongoing physical or mental symptoms. For example, if an ICD is placed then the DVLA must be informed and the patient cease driving for six months. Also, if the brain sustained a significant injury, further investigations may be needed before returning to drive. More information on this is available on the Sudden Cardiac Arrest UK website.

In situations where someone makes a good recovery, it may be that they become blasé about the experience. This could prove frustrating to you because you may still be having difficulty coming to terms with your own experiences around the resuscitation attempt and the subsequent recovery, and your loved

one may not appreciate this because they were not conscious at the time these distressing events occurred.

Although post-cardiac arrest symptoms are common and many will have an initially bumpy ride, most people can find a new balance in their life. They can adapt to the difficulties faced and find new opportunities for life satisfaction and happiness.

Current guidelines recommend that before being discharged functional assessments of physical and non-physical impairments are done to identify early rehabilitation needs and refer to rehabilitation if necessary. The survivor should also receive a follow up within three months after hospital discharge, including: screening for cognitive problems, screening for emotional problems and fatigue, and further information and support for the survivor and family members.

This leaflet has discussed several issues which may arise for someone who has suffered a cardiac arrest and how this may impact both the survivor and you as someone close to them.

You may feel numb, isolated, hyper-agitated and even reluctant to talk about your issues as you do not wish to draw attention away from your loved one who has been unwell. However, these feelings are very common and understanding the emotions you are experiencing may help you process the events and cope with their impact. We encourage you to talk these feelings through with those close to you and consider seeking professional support.

There are several 'self-help' strategies that many people find helpful to use during difficult times. Phone apps can be an easy way to access support and many are listed on the NHS mental health apps library.

Mindfulness, for instance, involves focussing your thoughts and feelings on the present moment. It aims to take people's thoughts away from what is troubling them in the hope of breaking cycles of self-blame and upset. Whilst it may not be for everyone, it can have tremendous benefits and there are a variety of ways in which it can be completed. Many people find apps such as 'headspace' are an easy way to start, and they can then adapt the process to suit themselves.

Sleep is intrinsically linked to wellbeing. Everyone has experienced feeling grumpy and then after a nap and waking up as a different person. When someone is experiencing psychological distress, there can be similarities, although there will be multiple other factors involved. If someone is turning over a distressing situation in their mind, they may have difficulty in getting to sleep leading to overtiredness which can have knock-on effects and lead to a worsening spiral of sleep deprivation. Many simple techniques can be employed to improve sleep including reducing caffeine intake (especially after midday), avoiding screens before going to bed and having a consistent bedtime routine.

If your loved one's cardiac arrest took place at home and the environment is triggering upsetting memories you may want to take practical steps to change your environment, such as rearranging furniture or changing the decor.

8 PROFESSIONAL SUPPORT

Some people might be particularly affected by a loved one's cardiac arrest, and will require support beyond the self-help strategies explained above. There are several ways of accessing this support and many types of support that can be provided.

One type of support is 'talking therapies' which can be accessed by directly seeking an expert in counselling, through your GP or by self-referring to the NHS service for improving access to psychological therapies (IAPT). Talking therapies such as Cognitive Behavioural Therapy (CBT) have been shown to benefit patients experiencing mild adjustment symptoms through to severe anxiety and depression.

If you are finding that talking therapies are not providing the required help, or you feel that you would not benefit from them then there are many other options. Most of these are best accessed through your GP. This may include Eye Movement Desensitisation and Resynchronisation (EMDR) therapy for those experiencing symptoms of post-traumatic stress disorder, or medication that can benefit a wide variety of psychological difficulties.

Useful Links

Information

suddencardiacarrestuk.org

chainofsurvivaluk.org

lifeaftercardiacarrest.com

icusteps.org

headway.org.uk

Facebook Peer Support Groups

For survivors and their families
SuddenCardiacArrestUK

For anyone who has participated in or witnessed a resuscitation
ChainOfSurvivalUK

Psychological Help

scauk.org/counselling

nhs.uk/mental-health

mind.org.uk

Bereavement

scauk.org/bereavement

sadsuk.org.uk

cruse.org.uk

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