Sudden Cardiac Arrest

A Guide for Survivors, Caregivers, Family and Friends

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Introduction

Sudden Cardiac Arrest (SCA) is a major killer around the world. Many people confuse a SCA with a heart attack, but as you will discover, they are nowhere near the same. While a heart attack is often survivable, this is not true for a SCA. The result is that those who do survive have special issues and needs that most people, including the person who had the SCA, know nothing about. This book is set out to assist everyone involved with someone who was lucky enough to have survived their SCA. It would be useful to read the entire book, but if not, then at least read the first section (*What Everyone Needs to Know*) and the Chapters that relate to your relationship with the SCA Survivor - partner, caregiver, family or friend. It is set out by information for the: Survivor of the SCA, caregivers to a SCA survivor, family and friends. As a SCA Survivor myself, this book has been put together to offer you information that is not readily available or supplied to you any other way. So please read, enjoy and learn. There are lots of examples and stories from SCA survivors and I highly recommend you joining the SCA survivors group on Facebook. This group has saved my bacon on several occasions and gave me hope when I felt like all was lost. Some of the stories are truly amazing, as are the people in this group. Good luck on this journey, and it is a
journey. Be patient, give it time and remember the brain is a remarkable organ. Its plasticity is amazing and we can rebuild our neural networks (mostly) so we never give up hope. Simply roll up your sleeves and get prepared to battle the effects of a SCA.

Thanks to the many contributors to this book and for the support from my family in writing it. This book is dedicated to anyone who has suffered a SCA, particularly those who have suffered any level of brain impairment. The road ahead is whatever you decide to make it, so make it a good one with as few bumps as possible. You’ve got this and you can do it! Good luck.

“If you don’t know how to die, don’t worry; Nature will tell you what to do on the spot, fully and adequately. She will do this job perfectly for you; don’t bother your head about it.”

– Montaigne
What Everyone Needs To Know

Ch 1 What is a sudden cardiac arrest?

Difference between a SCA and a heart attack

Many people consider a SCA the same as a heart attack. Wrong! They are vastly different (see Figure 1 for a visual representation of the differences). A heart attack is, in essence, a pumping problem where a part of the flow of blood gets partially or totally blocked in an area of the heart. The heart keeps pumping however and flow to the brain usually continues – although it might be slower. But blood still tends to circulate. Today, more than 90% of people survive myocardial infarction. That's the technical term for heart attack¹.

A SCA is an electrical problem where the heart ‘short circuits’ and stops pumping blood, either by beating so fast it gets no blood moving through the body and stops, or it simply shuts off and no blood flow is pushed through the body. With a SCA there is no pulse and the brain and body get no blood whatsoever. Worldwide survival rate is between 5- 6% of Out of Hospital SCA (OHCA).

¹Harvard Medical School (No Date) How heart attacks became less deadly. Harvard Health Publishing Retrieved online 21 Aug 2020 at:
https://www.health.harvard.edu/healthbeat/how-heart-attacks-became-less-deadly#:~:text=Today%2C%20more%20than%2090%25%20of%20interruption%20in%20the%20blood%20supply.
Figure 1. *The differences between a heart attack and a sudden cardiac arrest*. ^2

Cardiac Arrest vs Heart Attack  People often use these interchangeably, but they are not the same. Courtesy of the American Heart Association, *(No Date)* Retrieved online at; https://cpr.heart.org/en/resources/cardiac-arrest-vs-heart-attack

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^2 Cardiac Arrest vs Heart Attack  People often use these interchangeably, but they are not the same. Courtesy of the American Heart Association, *(No Date)* Retrieved online at; https://cpr.heart.org/en/resources/cardiac-arrest-vs-heart-attack
Cardiovascular disease and SCA

These two distinct heart conditions are linked. SCA can occur after a heart attack or during recovery. Heart attacks increase the risk for SCA, however most heart attacks do not lead to SCA. But when SCA occurs, heart attack is a common cause\(^3\). Other heart conditions may also disrupt the heart’s rhythm and lead to SCA. These include a thickened heart muscle (cardiomyopathy), heart failure, arrhythmias (an *arrhythmia* is a problem with the rate or rhythm of the heartbeat) particularly ventricular fibrillation, a disordered electrical activity which causes the heart’s lower chambers (ventricles) to quiver, or fibrillate, instead of contracting or beating normally. This prohibits the heart from pumping blood, causing collapse, which is a major cause of SCA. Long Q-T syndrome, also called LQTS—which is a disorder of the hearts’ electrical system—is yet another cause of SCA. The lower chambers of the heart (ventricles) take too long to contract and release\(^4\). But over to one quarter of SCAs have no cause\(^5\) (idiopathic) and the individual may have no underlying issues. These are the most difficult to understand.

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\(^3\) Sudden Cardiac Arrest - Symptoms and Causes. (No Date) *Mayo Clinic* Retrieved online 21 Aug 2020 at: https://www.mayoclinic.org/diseases-conditions/sudden-cardiac-arrest/symptoms-causes/syc-20350634

\(^4\) Heart Attack and Sudden Cardiac Arrest Differences. Last Reviewed: Jul 31, 2015 by the *Heart Organisation*. Retrieved online 22 July 2020 at: https://www.heart.org/en/health-topics/heart-attack/about-heart-attacks/heart-attack-or-sudden-cardiac-arrest-how-are-they-different#---text=A%20heart%20attack%20is%20when,is%20an%20%E2%80%9D%20problem.

**Idiopathic SCA**

Some SCAs are unable to be explained in medical terms. Mine was caused by a build up in fluid in my lung. Basically, I was drowning due to the fluid build up and my heart simply shorted out. Other people have also experienced SCAs without having cardiovascular disease. Often an SCA is the result of an underlying illness. Obesity, smoking, cancer, or other debilitating diseases can be causes of a SCA. For example, many people who died during the coronavirus pandemic in 2020 died of a SCA as a result of having Covid-19. This was the result of the impact of the coronavirus, but the cause of death was SCA. However, close to 25% of all people who suffer a SCA exhibit no signs prior to the event.\(^6\) This can cause the individual and their family a great deal of anxiety as an undiagnosed SCA leaves everyone wondering “will it happen again?”, “it’s probably only a matter of time now.” and everything in between. This isn’t always the case as many on the survivors websites will attest to. Just because you’ve had one idiopathic SCA doesn’t necessarily mean you will have another.

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Ch 2 How many people have an SCA every year?

**Number of SCAs**

There are varying estimates as to how many people die from a SCA in a year, but the latest report states that worldwide, SCA is the most common cause of death with between 99.5⁷ and 190 out of 100,000 adults experiencing a SCA yearly (that equates to between 5,500,000 and 14,800,000 deaths per year) and 12.2 to 19 out of 100,000 (250,000 to 385,000 deaths) young people (under 15)⁸. That equates to somewhere between 5,750,000 and 15,185,000 SCA deaths each year. Sirinivasan & Schilling (2018) believe the numbers of SCA deaths to be closer to 17,000,00⁹ per year worldwide. The major problem in getting correct numbers is reporting, in particular in Asia with high density populations such as India, Indonesia and China. SCA is the leading cause of death in the United States, causing nearly 450,000 deaths each year¹⁰. The average age for sudden cardiac arrest is 60, but anyone can experience it, including children and people in their

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⁹ Srinivasan, N.T. and Schilling, R. (20180 Sudden Cardiac Death & Arrhythmias Arrhythmia & Electrophysiology Review 7(2) 111–117.

30s and 40s who have no sign of heart disease\textsuperscript{11}. Global survival rates vary by country, from 1\% in China to 12\% in New Zealand, and 19\% in the Netherlands\textsuperscript{12}. In the United States, SCA appears among the multiple causes of death on 13.4\% of death certificates. This suggests that 1 of every 7.5 people in the US who die each year\textsuperscript{13} will die of a SCA. Not surprising as the survival rate of Out of Hospital Cardiac Arrests in the US is only 6-8\%. Globally, SCA claims more lives than;

- colorectal cancer,
- breast cancer,
- cervical cancer,
- prostate cancer,
- Alzheimer’s disease,
- suicide,
- auto accidents,
- HIV,
- firearms,
- and house fires

\textit{combined}\textsuperscript{14}

To put it in plain and simple math, worldwide as many as 18,000,000 people will have a SCA in the next 12 months of which 17,100,00 will die straight away, usually before they reach hospital. Of those that do survive to discharge from hospital, within 12 months only 630,000 will be left alive and after five years another 250,000 will be gone. So after five years post-SCA discharge from hospital only approximately 380,000 survivors will be left out of the original 18,000,000. That is a frightening statistic.

“No matter what statistical source you look at, the reality is the majority of people who experience a sudden cardiac arrest (SCA) will not survive. Since these deaths usually occur without warning, and their survival rates drastically decrease if treatment isn’t received within minutes of the onset of the cardiac arrest, the likelihood of an SCA victim leaving the hospital with all neurological function intact is slim.”15

**After survival**

Now, if you survived a SCA and are reading this, then count your lucky stars. At the end of June 2018 the National Academy of Sciences, Engineering and Medicine\(^\text{16}\) reported that:

> “Every year in the U.S., approximately 420,000 cases of SCA occur outside of a hospital (OHCA) setting, in which less than 6% survive. Approximately 220,000 SCAs occur each year in hospitals and 24% of those patients survive. Estimates suggest that SCA is the third leading cause of death in the U.S. behind the total of all cancers and coronary heart disease.”

Survival of a SCA can also be dependent on which country you live in too, how close you are to a hospital or an Emergency Medical Service (EMS), if there is an Automated External Defibrillator (AED) nearby, and if there is anyone handy who knows Cardiopulmonary Resuscitation (CPR). For example, in China the survival rate for an OHCA is less than 1%, in the United Arab Emirates is about 2.4%, 5.6% in Japan, close to 6-8% in the USA, 10.3% in the United Kingdom, in

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New Zealand and Australia the survival rate is just over 12%\textsuperscript{17}, while the rate in the Netherlands has increased to 19%. And time of the event can make a difference too. In a US hospital setting, survival on an In Hospital Cardiac Arrest (IHCA) is >20% if the arrest occurs between the hours of 7 am and 11 pm, but only up to 15% if the arrest occurs between 11 pm and 7 am.\textsuperscript{18} So don’t plan your SCA for the middle of the night as your chances of survival diminish.

Survival is also dependent on whether or not the sufferer receives CPR and/or an (AED) within the first few minutes.\textsuperscript{19,20,21} Both the United Kingdom, and New Zealand have public health systems and access to paramedics or EMS is usually close to the population centers. This is also true in the Netherlands where bystander CPR assistance is huge. Also, in New Zealand and Australia, many people are actively involved in the Surf Life Saving Clubs where CPR is mandatory for all participants to undertake. But as Dames\textsuperscript{22} states:

\begin{itemize}
  \item \textsuperscript{17} Epidemiology of Sudden Cardiac Death: Global and Regional Perspectives Wong, Christopher X. et al. Heart, Lung and Circulation, Volume 28, Issue 1, 6 - 14.
  \item \textsuperscript{22} Dames, S. J. The Trouble with Cardiac Arrest Statistics. Updated 7/31/18 with data from the American Heart Association’s 2018 update on Heart & Stroke Statistics Retrieved online 27 July, 2020 at https://www.aedsuperstore.com/resources/sudden-cardiac-arrest-statistics/
\end{itemize}
“No matter what statistical source you look at, the reality is the majority of people who experience a sudden cardiac arrest (SCA) will not survive. Since these deaths usually occur without warning, and their survival rates drastically decrease if treatment isn’t received within minutes of the onset of SCA, the likelihood of an SCA victim leaving the hospital with all neurological function intact is slim.”

So despite managing to survive the original event, you are still not totally out of the woods just yet.
Ch 3  What damage can a SCA do to you?

Introduction

If you have experienced an OHCA and didn’t receive CPR within the first three to four minutes, then it is likely there will be some brain damage. A brain deprived of oxygen for as little as three minutes starts to die. The dying process has been studied for years (since the early 1900s). There is a ‘reversible period’ which is classified as clinical death which lasts for up to 4-6 minutes. If intervention (CPR, defibrillation, and/or administration of epinephrine) is not instituted during this period and return of circulation restored (ROCT), then after approximately 6 minutes without intervention the person most likely will move into what is termed biological death where irreversible brain damage starts to happen. At the 10 minute mark irreversible brain damage is almost a certainty. After around 15-20 minutes without intervention, biological death will be complete and the individual is unlikely to recover. This is due to either global tissue hypoxia, an absence of enough oxygen in the tissues to sustain bodily functions, or anoxia, the total cessation of oxygen to the tissues. Even if a person is resuscitated, “...nine out of

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ten victims die”. and another 70% will be comatose and/or sustain some level of brain damage. Simply put, the longer the brain is deprived of oxygen, the worse the damage will be.

**Brain damage**

Following SCA, survivors will often experience damage to parts of the brain called the cerebral cortex, hippocampus, the cerebellum, and/or the basal ganglia. These are the areas that suffer first during an anoxic or hypoxic event lasting more than 4–6 minutes. Even the spinal cord may sometimes be damaged. Persons in a coma for 12 hours or more will usually experience lasting motor, sensory, and intellectual deficits. Recovery will often be incomplete and/or slow—on the order of weeks to months or even years—if at all. I had an anoxic SCA which lasted approximately 13 minutes. So I was extremely lucky to survive. According to Headway, the brain injury association in the UK:

“In anoxic brain injury, the actual nerve cell bodies themselves are very vulnerable to damage and this damage is irreparable.”

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Ch 4  Parts of the brain most affected by a SCA

The hippocampus

The hippocampus is a brain structure embedded deep in the temporal lobe of each cerebral cortex. It is an important part of the limbic system, a cortical region that regulates motivation, emotion, learning, and memory. It is an older part of the brain. The hippocampus plays important roles in the consolidation of information from short-term memory to long-term memory, and in spatial memory that enables navigation. We would not even be able to remember where our house is without the work of the hippocampus. The hippocampus also encodes emotional context from the amygdala. When you think of the amygdala, you should think of one word – fear. This is where the ‘fight or flight’ response resides which is critical to our survival. The brain is a complicated piece of machinery, but it can be worked on and regenerated. Exercise may be one of these effective treatments that can reverse brain atrophy. The location of these vital areas of the brain are shown in Figure 2.
The cerebellum

Coordination of voluntary movements is the function of the cerebellum, another part of the older brain. Most movements are composed of a number of different muscle groups acting together in a temporally coordinated fashion. One major function of the cerebellum is to coordinate the timing and force of these different muscle groups to produce fluid limb or body movements. This part of the brain helps a person drive, throw a ball, or walk across the room. The cerebellum also assists people with eye movement and vision. It is also essential in
maintaining balance. Damage to my cerebellum has caused me significant problems with my motor skills. This is common in many SCA survivors.

*The basal ganglia*

The basal ganglia and related nuclei consist of a variety of subcortical cell groups engaged primarily in motor control, together with a wider variety of roles, such as motor learning, executive functions like decision making, behavior and emotions. Again, the basal ganglia is associated with the old part of the brain and are strongly interconnected with the cerebral cortex, thalamus, and brainstem, as well as several other brain areas. The caudate nucleus is one of the clusters of neurons located in the basal ganglia that has long been associated with motor processes due to its role in Parkinson's disease. It plays important roles in various other nonmotor functions as well, including procedural learning, associative learning and inhibitory control of action, among other functions (Bailey, 2020).

*The cerebral cortex*

The cerebral cortex is the largest site of neural integration in the central nervous system. Herein lies your executive function area. It plays a key role in:

- Determining intelligence,
- Determining personality,
• Motor function,
• Planning and organization,
• Touch sensation,
• Processing sensory information,
• Language processing,
• and, an integral link between a person's will to live.

Attention, perception, awareness, thought, memory, language, decision making and consciousness, are just a few of the things that are important in everyday life! The basic activity of this brain region is considered to be orchestration of thoughts and actions in accordance with internal goals. It is also where our executive functioning resides. When this area is damaged, or the areas that supply it with information (such as the basal ganglia), then you potentially have issues with:

• **Self-awareness.** Simply put, this is self-directed attention,
• **Inhibition.** Also known as self-restraint or taking risks.
• **Non-Verbal Working Memory.** The ability to hold things in your mind. Essentially, visual imagery is how well you can picture things mentally.

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- **Verbal Working Memory.** Self-speech, or internal speech that people think of this as their ‘inner monologue’.

- **Emotional Self-Regulation.** The ability to take the previous four executive functions and use them to manipulate your own emotional state. This means learning to use words, images, and your own self-awareness to process and alter how we feel about things,

- **Self-Motivation.** How well you can motivate yourself to complete a task when there is no immediate external consequence,

- **Planning and Problem Solving.** Experts sometimes like to think of this as ‘self-play’, how we play with information in our minds to come up with new ways of doing something. By taking things apart and recombining them in different ways, we’re planning solutions to our problems,

- **Being consistently late.** Forgetting appointments entirely, or showing up late for appointments or special family items.

Obviously this area is critical for everyone and any damage to its functionality can be extremely difficult to work through. But knowing about this damage and what is affected is critical information for a SCA survivor and their family and friends who they will be interacting with over the course of their recovery.

I recommend any SCA survivor to request either a Computed Tomography (CT) or Magnetic Resonance Imaging (MRI) scan to study any affected regions of
your brain. With this information, you and your partner and family will know what to expect and then you can prioritise what to work on first during recovery.

*CT scan images*  
*MRI scan images*

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**Ch 5**  
Computed tomography scan (CT) and magnetic resonance imaging scan (MRI)
So why a CT or MRI? Anyone who has been clinically dead for over 3-4 minutes is likely to suffer damage to one or more of the areas listed above. Ensure you receive a CT or an MRI to find out which areas have been most affected. Both of these techniques take ‘pictures’ of different slices of your brain and can identify areas of damage. They are very reliable and extremely useful and understanding the results will help with your recovery. Figure 3 shows a brain scan exhibiting damage to the basal ganglia and caudate nucleus. Note how the basal ganglia is now white, exhibiting damage and the caudate nucleus shows dark (in the middle between the white areas). This also exhibits damage. Other dark areas also suggest damage to other areas of the brain.

Figure 3. **Before and after CT exhibiting damage to the basal ganglia and caudate nucleus as well as the prefrontal cortex.**

![Before and after CT scan](image)

Note the darkness in the middle of the brain area and the spot pointed out by the arrow. Also note the darker areas at the front of the brain in the prefrontal cortex.
areas. Also the dark spot on the right side of the brain (see the arrow) will affect the left side of the body. These are significant impairments for this patient.

So, given it is easy to see where the brain damage is most likely to be located, one can better understand why most SCA survivors have no recollection of the SCA event, have memory problems directly after the event and, in some cases, long-term memory loss, and why motor skills are often disturbed making the little things difficult to accomplish. For me, I have no memory of the event and little memory of the three to five months following. During recovery I also suffered walking issues, balance problems, eating coordination issues, some bladder problems and putting on socks is still all but impossible without falling over! But slowly I am making progress on each of these issues, maybe not as fast as I would like, but progress nonetheless.
So it’s no walk in the park, but there are things that can help. But a proper scan of your brain and an explanation by a neurologist will be a great starting point for recovery.

Ch 6 What treatments are available?

*Getting an implantable cardioverter defibrillator (ICD)*

Many people who suffer a SCA due to a heart attack or coronary heart disease will end up with an implanted device to kick start their heart should they have a recurrence. These are called ICDs for short. Obviously they require a surgical procedure to implant, but this is a relatively straightforward procedure and often you will be discharged on the same day. An ICD is used to send a short electrical impulse directly to your heart should it go into an abnormal rhythm. These are effective devices to help ensure you don’t experience another SCA. They tend to last up seven years and the lithium battery will then need to be replaced. The ICD has leads that connect to your heart and an implantable device that is usually placed under the skin on your left side. These are very reliable and used
regularly, particularly in the US. Don’t be afraid of having an ICD implanted. They will be more than likely to give you many good years to come.

Figure 4. An ICD and its placement in the body.

There are some issues that you need to be aware of. First, for about a month after surgery, the Mayo Clinic suggests you refrain from:

- Vigorous above-the-shoulder activities or exercises, including golf, tennis, swimming, bicycling, bowling or vacuuming (darn),
- Lifting anything heavy,
- Strenuous exercise programs,
- and to avoid contact sports indefinitely. Heavy contact may damage your device or dislodge the wires.

It is also recommends to totally refrain from being close to or using certain electrical devices such as

29 Implantable Cardioverter Defibrillators (ICDs). *Prepared by Mayo Clinic Staff.* Retrieved online 21 July 2020 at; https://www.mayoclinic.org/tests-procedures/implantable-cardioverter-defibrillators/about/pac-20384692
- **Cellular phones and other mobile devices.** It's safe to talk on a cellphone, but avoid placing your cellphone within 6 inches (about 15 centimeters) of your ICD implantation site when the phone is turned on. Although unlikely, your ICD could mistake a cellphone's signal for a heartbeat and slow your heartbeat, causing symptoms, such as sudden fatigue.

- **Security systems.** After surgery, you'll receive a card that says you have an ICD. Show your card to airport personnel because the ICD may set off airport security alarms.

- **Hand-held metal detectors** often contain a magnet that can interfere with your ICD. Limit scanning with a hand-held detector to less than 30 seconds over the site of your ICD or make a request for a manual search.

- **Medical equipment.** Let doctors, medical technicians and dentists you see know you have an ICD. Some procedures, such as magnetic resonance imaging, magnetic resonance angiography, and radiofrequency or microwave ablation are not recommended if you have an ICD.

- **Power generators.** Stand at least 2 feet (0.6 meters) from welding equipment, high-voltage transformers or motor-generator systems. If you work around such equipment, your doctor can arrange a test in your workplace to see if the equipment affects your ICD.

- **Headphones.** Headphones may contain a magnetic substance that can interfere with your ICD. Keep your headphones at least 6 inches (about 15 centimeters) from your ICD.
• **Magnets.** These might affect your ICD, so it's a good idea to keep magnets at least 6 inches (15 centimeters) from your ICD site.\(^{30}\)

Contrary to popular mythology, the Mayo Clinic suggests there is little or no risk to your ICD from microwave ovens, televisions and remote controls, AM/FM radios, toasters, electric blankets, electric shavers and electric drills, computers, scanners, printers, and GPS devices.

*My suggestion for a care team*

Other survivors won’t need an ICD. Almost all survivors need other treatment, from medications for cardiovascular disease or mood, to physical and psychological therapy. Treatments will obviously vary by the level of your need, where you happen to live and your financial circumstances. Your doctors will guide you towards the best treatments they can offer, but you may be left feeling like you don’t have everything you need. You may want to seek out others to assist in preparing a treatment plan to meet your specific needs. As a guideline, I suggest you will need the following to optimise your chances of recovery:

• A neurologist

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\(^{30}\) Implantable Cardioverter Defibrillators (ICDs). *Prepared by Mayo Clinic Staff.* Retrieved online 21 July 2020 at; https://www.mayoclinic.org/tests-procedures/implantable-cardioverter-defibrillators/about/pac-20384692
• A cardiologist
• A psychologist and psychiatrist
• A physiotherapist
• A sponsor or motivator (could be a friend or partner)
• A great general practitioner or primary care physician

Your neurologist

A good neurologist needs to understand the issues of a SCA survivor and show some understanding of the need for information to assist in the healing process. Also to explain the plasticity of the human brain and how new neural networks can be formed or rewired so you can get some, if not most, of your functionality back over time. This starts with the CT or MRI and a full verbal and written explanation (because you are likely to forget what you are told) of the damage that has occurred to the brain and the ramifications of that damage in the short to medium to long term. The brain is a remarkable organ and it was once thought brain cells could not be regenerated. That is no longer scientific dogma. Damaged areas of the brain can be rewired or gotten around by creating new neural networks through the ‘Use it, or Lose it’ principle. There are hundreds of tools and mind games in the market now to assist you in this endeavour, all claiming to assist you in getting your memory back. I found Brain Games, Elevate and Word Stack
extremely useful for me and very cost effective, but simply shop around to find out what works best for you. And occasionally check in with your neurologist just to confirm you are making progress.

*Your cardiologist*

As many as half of all SCAs are the result of cardiovascular disease, so you will require a good cardiologist with a strong understanding of what a SCA is and the ramifications for you in regard to any brain issues. Don’t let them leave you out of the loop and in the wilderness as this can be frustrating and increase your anxiety. Often they will simply put in an ICD and then check on you intermittently or only if something goes wrong. You will need and want more from them than that so ensure you and your physician keep the lines of communication open.
**Your psychiatrist and psychologist**

Fear, anxiety, denial, and depression are common emotional responses to illness and can prevent the individual from returning to previous activities and leading a normal life. A psychiatrist can help with mood swings, depression, and Post Traumatic Stress Disorder (PTSD) which often follow an SCA. They can prescribe medications that will lessen the severity of the depressive episodes, any anger management problems or general unease with your situation. As anyone who has had an SCA will tell you, *you are simply not the same person that you were before your SCA.* This alone is hard enough to come to grips with and this is where a good psychologist will be invaluable. The issue that is most often repeated by SCA survivors is that “no one seems to understand I’m not the same person as I was before the event”. Yes, I might look, sound and mostly act the same, but I am not! I guess dying has a way of changing you that is indescribable. Anxiety is something that many of us need to learn to control. Talking to my psychologist has helped me keep my perspective and control my emotions and reactions to those around me who don’t, and perhaps never will, understand what it is like having survived a SCA. Plus the antidepressant drugs prescribed by my psychiatrist have been super useful.
Your physiotherapist

For those of us with motor skill problems, these can be overcome with practice, but you have to know what to practice! This is where a good physiotherapist is essential, one who has a knowledge of neurological issues that will be affecting you. A physiotherapist has specialist knowledge necessary to assist you in regenerating the specific neural pathways to assist you in recovery. You will be given specific tasks and exercises to help you on your journey, with an explanation as to why and how these will help. I was lucky enough to find two in my small town in New Zealand and both were awesome. While I had to pay for their services, it was very affordable (about $60.00 per hour long visit) and worth every cent. We met only every second week to start and then once a month after that so the cost wasn’t prohibitive but the progress was immense. Just little tips they provided made all the difference and I urge you to find a physiotherapist to assist you if you suffered any motor skill problems at all after your SCA.
Your partner or motivator

Finding a partner or motivator can be problematic. Often a partner or child is too close and, unless you have a special relationship with them, it can be stressful and often destructive. But your partner knows you best and, if they are able, I suggest they take over this role. My partner is a very busy woman with a highly demanding job so I was lucky in that I have daughters who really provided me with the motivation and assistance I needed. One provided the empathy and listening ear I required at times in a non-judgemental manner, while the other was the ‘bossy boots’ who got me off my backside and made me do what I needed to do to get fit and regenerate the necessary neural networks for better efficiency. While I was lucky to have these two to help me, if you have a friend or acquaintance who can act as a motivator, that would be useful if your partner is not able to help. Whoever it ends up being, give them your all and be understanding and do what they ask as much as possible. They will rejoice in your progress and ensure you give them a good portion of the credit!

Your general practitioner or primary care physician

Finally, a good General Practitioner (GP) or Primary Care Physician (PCP) is extremely important, one who understands your issues and can see them from
the big picture perspective. These people can be hard to find and you might need to leave your old GP or PCP and find one that can be more helpful. Remember, your old GP treated the old you, not the new one you have become. And you don’t owe them anything. Doctors provide a service, just like a mechanic or carpenter or plumber. So if they have no understanding of the trauma a SCA can cause, or any understanding of the neurological issues surrounding a SCA, then find one who does. This is the person you will complain to about your partner’s impatience, your boss’ unwillingness to understand your memory isn’t good, your frustration at friends who find you disengage from them, and every other issue you will uncover along the way. They will also work together with your cardiologist, psychologist, psychiatrist and physiotherapist to ensure you are getting the best possible care and have the best possible chance to optimise your recovery. I changed my GP almost straight away as my previous doctor was totally out of his depth. It was easy in New Zealand, but can be more difficult with some insurance companies in the USA. But if you can, ensure you have a GP or PCP who understands your emotional and physical needs. This will become more and more important as you move along your journey to better emotional, physical, psychological and social relationships. Remember, this is a major journey, perhaps the biggest one you will
ever undertake, and you want someone by your side who understands you, your needs and your situation, both physically and relationship wise.

Your team

Your partner or caregiver, GP and you will need to develop a full treatment programme that will take a holistic approach to your issues. Your GP or PCP may control the medications issued by your psychiatrist, cardiologist and neurologist and will work closely with you to ensure your medications are right for you. This doesn’t tend to happen as much in the US as the medications are issued independently by each specialist, but in some countries it is your GP who controls and writes the prescriptions for your medications. Ensure they check:

- you still require the medications prescribed,
- that doses are correct,
- if there are alternative medications available that are better or less expensive,
- if other medications are required from which you may benefit,
● if any of the medications are contraindicated,
● for any general concerns or questions you may have,
● on your general progress physically,
● that you are suffering no medication side effects.

A full treatment plan also includes your workout schedule determined between you, your caregiver and your physiotherapist. Your partner, caregiver or motivator may want to go with you to all of your GP and physiotherapist visits so they can provide unbiased feedback on your progress.

*Let’s talk about drugs, shall we?*

I have been on so many drugs I have lost count! Now I take an antidepressant (Venlafaxine), a beta-blocker for blood pressure control (Bisoprolol), a statin for cholesterol (Pravastatin), a reflux medication (Omeprazole), a diuretic (Furosemide), an anti-anxiety medication (Candesol) and others, including Vitamin B12, an Iron tablet and an ‘Over 50s’ multi-vitamin. It’s almost a meal! The key is to ensure you need them all over time and, if you are having lightheadedness and/or other issues, check side effects with your GP or PCP and change medications if necessary. I had to change my blood pressure drug from Metoprolol to Bisoprolol as I got very dizzy on Metoprolol. You will have to
simply use trial and error. Hopefully you won’t have to change much. Many of these drugs have side effects so be aware of what these are. If you suffer from any of these, talk about them immediately with your GP.

Recreational drugs

DON’T use illicit drugs as these can have deadly interactions with your prescription medications. In particular, cocaine can be deadly\textsuperscript{31}, but any drugs can be harmful and cause you more problems than they are worth. So be warned and be very cautious if you are considering dabbling in recreational drug use.

Ch 7 Why don’t we hear more about SCA?

Promoting sudden cardiac arrest awareness

This is a very good question and one I’m not totally certain I can answer. It is the number one killer in the world and third in the USA, only behind all cancers combined and death to cardiovascular disease. But how often do you hear people talk about someone who died from an SCA? And is there an SCA Day (like for Lou Gehrig’s disease (ALS) or childhood cancer), or a fundraising event like there

\textsuperscript{31} Illegal drugs and heart disease. (No Date). Retrieved online 20 Aug 2020 at: https://www.heart.org/en/health-topics/consumer-healthcare/what-is-cardiovascular-disease/illegal-drugs-and-heart-disease
is for breast cancer, or even any major reports on SCA research that make the news? The answer is no. I couldn’t even find a pamphlet or piece of paper in the doctors or specialists offices (or the hospital for that matter) that explained anything at all about an SCA and the ramifications of surviving one. So what’s the story? Why don’t we talk about this problem killer rather than just pretending it doesn’t happen? Are there so few of us who survive that it’s not worth the effort to provide us with information? Oh wait! There is a SCA awareness Month!!! Oh goodness gracious me. Can anyone tell me what month it is? No? Really? Funny that!

It’s actually in October.

Even when you search for information you might get the wrong SCA. How about this.
I Googled SCA logos and got the one below. Nice, eh? Unfortunately it’s not for SCA people, it’s the logo for the Sexual Compulsives Anonymous group. Sorry! I think they have an even higher profile than our SCA!

Too hard basket

I’m not certain but I believe it could be because SCA Survivors are just in the too hard basket and no one really understands how to approach the topic as the level of damage to the individual varies between patients. But we can all do our bit to change that.
Ch 8   Learn CPR

For the 70% of individuals who have an Out of Hospital Cardiac Arrest (OHCA), having someone handy who knows how to do CPR is essential to their survival\textsuperscript{32}. Another study identified “\textit{CPR initiated by a bystander as a strong and independent predictor of improved functional outcomes for survivors from OHCA}\textsuperscript{33}.” So here is a quick lesson on applying CPR effectively. Be prepared. You never know, the life you save may be the one of the person you love most!

The best method to learn CPR is taking an accredited first-aid training course. It includes how to perform CPR and how to use an AED. But for the time being, here is something that might get you through until you can take a proper course. There are six critical components of high-quality CPR:

- proper hand configuration and placement,
- provide compressions of adequate rate,
- the optimum depth of compression,
- avoid leaning between compressions,
- minimize interruptions in chest compressions,
- avoid excessive ventilation.


\textsuperscript{33} Steill I, Nichol G, Wells G.\textit{et al} Health-related quality of life is better for cardiac arrest survivors who received citizen cardiopulmonary resuscitation. \textit{Circulation} 20031081939–1944.
We will discuss each in their own right below. But first, call 911 or 111 or whatever the emergency services number is in your country. They will assist you in offering CPR if you do not know how to do it.

Gently lay the person on a clean area of the floor as they will need to be on a solid surface. A bed is too soft. Continue calling out to them if they appear unconscious. Check to ensure there is nothing stuck in their airways and check for a pulse. If there is none, start CPR immediately.

Figure 5. Correct hand placement and configuration for CPR.

**Hand configuration and placement for chest compressions**

With two fingers, locate the point where both sides of the bottom of the rib cage come together. This is the bottom of the sternum or breastplate. Holding your fingers as a place marker, place the heel of your other hand just above your fingers. Then remove your two fingers and place that hand on top of the other hand,
interlacing your fingers. Straighten your arms and, using your upper body, press down on the person's chest. For a fuller understanding of hand placement and CPR, see the YouTube video available online at\textsuperscript{34}. Or view the Youtube video at\textsuperscript{35}:

https://www.youtube.com/watch?v=fy9vihJ8mqk.

\textit{Provide compressions of adequate rate}

Try to keep the compression rate at a minimum of 100 per minute but not more than 120 per minute. Think of the tune \textit{Staying Alive} by the Bee Gees. This is about the correct rate. This will ensure the blood flow will be adequate to hopefully keep the individual alive and minimize damage to the brain. Chest compression rates between 100-120 per minute are shown to be the best rate for survival of the patient. This is hard work so be prepared to keep it up until help arrives. If possible, get someone else involved and when you feel too tired to keep up the pace, let them take over while you have a rest.

\textit{Depth of compressions}

Compressions need to be between 45-50mm, or about 2 inches. This is a tall order as that requires some good strength and will undoubtedly result in cracked or

\begin{enumerate}
\item \textsuperscript{34} CPR is the key to survival of sudden cardiac arrest (22 June 2018) Retrieved online 4 July 2020 at: https://www.heart.org/en/news/2018/07/12/cpr-is-key-to-survival-of-sudden-cardiac-arrest
\item \textsuperscript{35} In a Nutshell: hand placement for CPR. youtube video. Retrieved online 20 Aug 2020 at: https://www.youtube.com/watch?v=fy9vihJ8mqk
\end{enumerate}
broken ribs for the patient and possibly a broken sternum. But the other option is death and/or severe brain damage and I know which I would choose. In fact, the person who ended up giving me CPR broke nearly all of my ribs and my sternum. But I am not complaining and am extremely grateful to them for doing so! So don’t be afraid to do damage by pushing too hard. Remember, the person is already clinically dead and you are trying to bring them back to life. So their life depends on the rapidity and depth of your CPR! So remember the 2 inch rule! You really have to push hard to achieve this, but just think of the result if you don’t.

_Avoid leaning between compressions_

This means exactly what it says. Don’t rest on the person's chest before the next compression. You want to allow the chest to fully expand without moving your hands off the specific spot you want them to be at for each compression. So no leaning or resting on the patient.

_Minimize interruptions in chest compressions_

CPR is hard work! If someone else is nearby, instruct them to get prepared by kneeling on the other side of the person with their hands ready, before you get tired. Let them know you are tired and count down with them to take over and continue counting to help them find their rhythm. It is more important to ensure the
continuation of compressions is kept up than ventilation, so don’t slow down, even when it starts to hurt!

Avoid excessive ventilation

The metabolic demands for oxygen are substantially reduced in the patient in cardiac arrest such that chest compressions are more important than breathing. In fact, it is not even necessary to breathe for a cardiac arrest patient for about the first two critical minutes as their blood is already fully oxygenated and enough will get to where it needs to be during this time.\(^{36}\) It may also allow time for someone else to arrive and assist with the breathing, allowing you to continue with the necessary frequency of compressions.

Providing breaths can distract a single bystander from quality chest compressions and is discouraged. If you are alone performing CPR for a loved one you may want to provide breaths by lifting their chin (tilting their head back to open their airway) pinching their nose and breathing into their mouth. If so, prioritize compressions and remember that a rate of 6-8 breaths per minute is more than adequate. And remember you don’t need to blow too hard, you don’t need to

see the chest rise for there to be a positive effect. Any breathing is better than none but quality chest compressions are most important for a SCA victim.

**Summary**

The location of an SCA and implementation of CPR is vital to survival.\(^{37}\) Being in a hospital will increase your chances of surviving. In America 24\% of SCAs that happen in hospital result in survival, compared to only about 6\% outside the hospital.

The facts are clear cut: immediate CPR, especially if administered immediately after cardiac arrest, can double or triple a person's chance of survival, up to 45\%.\(^{38}\) So take a CPR class as soon as you can and remember, the life you save may be that of a loved one! CPR is important for everyone to know. So sign up everyone involved right now! It is that important.

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Ch 9  How to use an automatic external defibrillator

Use of an AED along with CPR further increases the chances of surviving a SCA. Introduction of the use of an AED within the first several minutes can increase survival rates up to 70% and reduce the risk of hypoxic or anoxic brain damage significantly. Learn to check where AEDs are stored in your favorite public places or at your workplace.

According to the Red Cross, there are 7 simple steps to use an AED. They are as follows:

1. Turn on the AED and follow the visual and/or audio prompts.
2. Open the person's shirt and wipe his or her bare chest dry. If the person is wearing any medication patches, you should use a gloved (if possible) hand to remove the patches before wiping the person's chest.
3. Attach the AED pads in the locations described, and plug in the connector (if necessary).
4. Make sure no one, including you, is touching the person. Tell everyone to “stand clear.”
5. Push the “analyze” button (if necessary) and allow the AED to analyze the person's heart rhythm.
6. If the AED recommends that you deliver a shock to the person, make sure that no one, including you, is touching the person—and tell everyone to stand clear. Once clear, press the “shock” button.

American Red Cross (2020). 7 Steps to Use an AED. Retrieved online 4 August 2020 at: https://www.redcross.org/take-a-class/aed/using-an-aed/aed-steps
7. Begin CPR after delivering the shock. Or, if no shock is advised, begin CPR. Perform 2 minutes (about 5 cycles) of CPR and continue to follow the AED's prompts. If you notice obvious signs of life, discontinue CPR and monitor breathing for any changes in condition.

Proper use of an AED will restore normal heart rhythms and blood will flow to the brain and body again. However, there are some situations where you must listen to the machine! For example, after my heart was restarted it immediately went into ventricular fibrillation, where it beat too fast to pump any blood anywhere! This required several minutes and a couple of shocks to finally get my heart into a normal rhythm. So just because they might be breathing or have a pulse does not mean they are out of the woods entirely. The machine will tell you if another shock is necessary so go through the proper procedures again if required. And check around your workplace or places you frequent to see if they have an AED handy and where it is located just in case. Proper use of an AED will increase the chances of survival of the patient significantly. CPR combined with AED
utilisation within the first 4 minutes results in about a 70% chance of survival to hospital in an OHCA.

I hope you have enjoyed this book so far, but this next section is mainly for the SCA survivor, but you should read it as well. It might provide you with some insight as to just how your loved one or friend is thinking and feeling: about you, the family, friends and the world in general. But be warned, it isn’t an easy read!
For the Survivor

Ch 10 So you survived - How am I different?

*How am I different now*

Well, you beat the odds and survived. Good job. But I have little doubt there will be times over the next year or so that you will ask yourself: ‘*What for? Why me? What did I do to deserve this?*’. Even suicidal thoughts may enter your mind, and, if they do, discuss this with your caregiver and/or psychologist. It is not uncommon to experience suicide ideation after an SCA. There are numerous social media groups that are specific to SCA survivors and you hear these sentiments voiced on a regular basis. It isn’t easy when you forget what you went to the store to buy, or where you left your phone, or what day it is, or where you are in time and space, or how to tie your shoes, or what your partner just asked you to do less than a minute ago or even how to put one foot in front of another. While you look the same from the outside, the internal turmoil can be tumultuous. And what’s worse, you don’t remember anything about the event, often before or after! This feeling can persist for some time: weeks, months and often years.

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What was dying like?

While others suffer from the trauma and/or PTSD as a result of watching you die, you don’t remember a thing and felt only a peace at the time. My son-in-law watched me code and still suffers from the trauma that caused him. So while it isn’t easy to come to grips with the new and different you, it is equally difficult to comprehend what those who love you went through. So remember to cut them a little slack as well!

So many people will ask you “What was it like? Did you see anything or meet anybody on the other side?” Here are some comments from survivors off the Sudden Cardiac Arrest Survivors website:

- I woke up with a feeling of peace. But, no memory of anything else.
- After the sudden cardiac arrest, the fear of death vanished for me. It was just “a peaceful, easy feeling” to quote the Eagles.
- I'm the same. I no longer fear death....I just don't want it 😊
- I felt just a peace like I've never felt before. I didn’t see a shining light or God or any lost relatives, I just felt this wonderful peace and I no longer fear dying.
- I don't remember anything, other than feeling very at ease and calm.
- Whatever your belief, just embrace today and keep moving forward, day by day. It takes time but we all recover in different ways. For our loved ones, watching us, it’s hard.
- I think it’s all just what you believe in. If you believe he's watching over you, then he is.
So for most, it was just a peaceful calm feeling, but others, dependent upon religious and other personal beliefs, it was something a bit more:

- I saw my Grandmother. She said I wasn’t ready yet, but she looked so beautiful. I didn’t want to leave her. But she sent me back.
- I saw beautiful white lights then clouds and I felt I was in heaven. Then my dad spoke to me, and then I woke up.
- It was so beautiful and calm. I saw my family who had passed some time ago and they looked so concerned to see me. They told me my time wasn’t now and they hugged me and I came back to Earth.
- I had a total out of body experience. I looked down and could see the trauma unit working on my body, but I wasn’t there. I started to drift away into this peaceful place but then woke up in my own body. It was an amazing experience and made me think there must be an afterlife.

Who knows what the real answer is to this question. It has been asked from time immemorial. I guess only when our time truly comes will we know for sure. But remember to tell yourself:

“...there is only one thing we say to Death… not today”\(^4\)!

\(^4\) Quote from *The Game of Thrones*, Series 1. Episode 3. Syrio Forel, swordmaster, says to Arya Stark “What do we say to the God of Death? ... And there is only one thing we say to Death: 'Not today.'”
Ch 11  So here’s the skinny on survival

SCA is traumatic for survivors, but also can be life-changing for their loved ones. It is common for both survivors and family members to experience challenges adjusting to life after cardiac arrest. For the survivor, feelings of fatigue, anxiety, withdrawal, fear, loss of interest, depression, loneliness, inability to relate to others are all common issues. They will also likely experience the ‘why me’ syndrome which can often lead to suicidal ideation. For the partners and family, feelings of frustration, anxiety and ‘why us?’ are also common, and the change in lifestyle will be dramatic for most. Here’s why:

- **90%** of SCA survivors experience impairment in performing daily life skills,
- over **40%** of patients experience symptoms of anxiety after SCA,
- **35%** with ICDs require coping skills to address fear of potential shocks,
- a typical adjustment period can take 6-18 months or longer with maximum recovery averaging over two and a half to three years. However, as you will discover on the Survivors websites, there are any number of people who have survived many years after their SCA and claim to continue to get better. So who knows for sure.
- over **50%** of SCA survivors are diagnosed with psychiatric disorders.
- most experience guilt (the ‘why me’ syndrome) which affects everyone,

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100% of everyone involved will have a change of lifestyle.

We are all different

It is hard to discuss each issue, as SCA is specific to the individual. Some have extreme brain damage which can mean depending on machines for survival, while others have very minor or no cognitive issues. It all really depends on how long your brain was deprived of oxygen. Remember, anything over 4 minutes will result in some damage. But if there is someone who is able to apply effective CPR within that time and/or apply an AED to restart your heart, your brain will at least receive some blood and the effect will be mitigated. In fact, if CPR commences immediately after the SCA and an AED is used to restart blood flow within the first few minutes, then the survivor faces their best chances of little or even no brain impairment.

Motor skill issues

The most common change as a result of anoxia or extended hypoxia is atrophy of the cerebellum resulting in loss of fine coordination of muscle movements leading to unsteady and clumsy motion43. This can be frustrating and

even tying your shoes can become a problem. Simple remedy - purchase a pair of slip on shoes and a long shoe horn so you don’t have to bend down to put them on. If you think outside the square, there are solutions to most things.

Eating can also be challenging. The good news is that we have to eat and practice makes perfect as they say. So don’t give up. Use your knife and fork and do exercises that assist your dexterity. Your physiotherapist will know which ones these are and you just need to be diligent in practicing them.

For DIYers, don’t pick up the hammer just yet! I have the sore thumbs to prove this isn’t a great idea right now! Even using a screw driver drove me (and my partner) crazy. Do only what you are confident you can do. Painting isn’t too difficult, and I glued on over 8,000 2.25cm (1 inch) square individual tiles in our kitchen and bathroom - one at a time. It was great rehabilitation and I was so proud of the result. Yes, each one pulled off the backing mat and then fixed individually with glue. Proud? You bet!
Dexterity and balance

Some people will shake, similar to Parkinson’s patients. I was one of those. My physiotherapist got me going to a special *CounterPunch* class at the local boxing gym. These programmes are set up particularly for Parkinson’s sufferers, but also took in people with brain injuries, like me. It was brilliant. They had specific exercises and drills that forced me to coordinate my actions, learn dexterity again, use my feet and hands in a more coordinated fashion, and relearn how to move from side to side and backwards without falling over. It was a revelation and I never knew such courses even existed! In addition, I made some
really good friends and that was an extra bonus. Great programme. See if there's one in your area, find it and go. Yoga is also good and learning meditation techniques is very helpful for your mental as well as physical health. Tai-Chi is also useful in regaining balance, fitness and mindfulness. There are so many programmes available in your community once you start looking. One male SCA survivor actually started taking ballet lessons to get his coordination back. He was no Nureyev, but he enjoyed it and made excellent progress with his balance and coordination. He even took part in the year end production! So look around and see what is available for you close to home.
Ch 12  I’m just not me! Your mental health

“I’m not the same person I was prior to my SCA.”

This sentiment is voiced by nearly everyone who experiences a SCA. Well of course you aren’t! How many people do you think—if they died and then were brought back to life—would have the same view of life as they did prior to the experience? This is a life changing event and you went through it. Now you have to learn to live with it.

Dangers of not being me

You look the same, probably sound the same, appear to be the same to everyone else, but only you know you are not the same as you were pre-SCA. You feel disengaged, fatigued all the time, have brain fog, don’t remember things like you used to (or at all), can’t do the things you used to love doing, are on all types of medications which are bound to have some side effects, and you have no memory of the event, or like me, the months that followed.

“As the degree of anoxia becomes more pronounced, confusion, agitation or drowsiness appear and there may be brief jerks of the limbs (myoclonus)
and seizures, both resulting from the damaging effects of lack of oxygen on the brain”.44

It’s almost like living in a dream (or nightmare) from which there doesn’t seem a way out. You feel like those around you don’t understand, and they don’t. How could they? They didn’t die and come back or suffer from any level of brain damage. So this is something that can cause you great anxiety and you will need to discuss this with your psychologist. You may never fully come to grips with an answer, but you will need to learn to deal with it as you can’t use it as an excuse or you run the risk of driving those you love away. I tend to simply try and suppress those feelings by accepting that they are mine and mine alone and I can’t expect anyone else to feel the same way. This is also when I tend to go to the SCA Survivors Group45 simply to remind myself that I’m not on my own. This is tremendously helpful.

45 Go to FaceBook and type in Sudden Cardiac Arrest Survivors Group or Sudden Cardiac arrest Survivors and Friends. Either of these are excellent. Also, the Sudden Cardiac Arrest Association has groups and very useful information. They can be found online at: https://associationdatabase.com/aws/SCAA/pt/sp/edmaterials
Memory loss

The loss of memory is a frustration at best and a major hindrance and problem at worst. My short-term memory is the cause of angst in our household as my wife can ask me to do something and I’ll say “yes” only to forget what she asked me to do seconds later. Or I will stand in the supermarket and can’t remember what I came there to buy. Or I will forget an important appointment. And the list goes on.

A simple strategy that I have utilised is to make a list or put appointments in my iPhone calendar with reminders. If I do this immediately then I don’t forget them. A shopping list is also mandatory or I will just buy whatever looks good and forget what I was supposed to purchase. This is not only expensive, but raises the ire of family members. No system is perfect however, so don’t be too hard on yourself if you forget something. It’s just part of your brain you will work on improving over time!

Luckily there are lots of online memory games that, if you work at them, do help. I particularly like Elevate, Brain Games and Wordstack. All three have been developed to assist people enhance their brain functionality and are excellent at providing you with feedback. The games are challenging yet fun! But it doesn’t
matter which you choose, just dive in and start working your memory again. Remember the ‘Use It, or Lose It’ principle. It is really up to you.

**Doing dumb things**

At least half of SCA survivors will suffer problems with their executive functions due to damage to the prefrontal cortex and parts of the basal ganglia and subcortical nuclei embedded there. This results in something similar to ADHD in children. As Fanning argues;

“Executive function can be thought of as the command central of our cognitive skills. These are the skills we use to get things done, plan and organize, not procrastinate (task initiation), not do things we shouldn't do (Inhibition/Risk Taking), respond to changing situations (shift) and monitor our own performance. Two major cognitive skills involved in executive function are working memory and emotional control.”

**The eight key executive functions**

Executive functions are skills every person uses in order to process and act on incoming information. The eight key Executive functions are utilised together to get us through each day. They are simply described below:

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46 Fanning, J. (Oct 18, 2017) 8 Key Executive Functions. Learning Success Retrieved online 7 July 2020 at: https://www.learningsuccessblog.com/8-key-executive-functions-infograph
1) **Emotional Control** - The ability to modulate or deal with feelings. In most cases, rationalizing is ineffective. It can be used to understand feelings after the fact but you cannot rationalize away an emotion. Impulse control helps you avoid risky behaviour and forces you to think before acting.

2) **Inhibition** - This is the ability to control your own thoughts and actions. For some SCA survivors, actions can come before or without access to the thought that produced the action. The impulsive action seemingly comes out of nowhere but is actually a function of damage to the prefrontal cortex. Mind-body techniques develop access to the underlying thoughts and the ability to control them. Survivors with weak emotional control often overreact and do not take criticism or negative comments well.

3) **Working Memory** - This consists of several forms of memory that all work together. Visual memory, visual memory manipulation, auditory memory, and spatial memory. These are all connected through spatial awareness. Your survivor may have problems remembering things, even if you have repeated them often and supplied notes.

4) **Initiation** - The ability to start a task. Often the survivor will have absolutely no idea where to start the task and will either procrastinate or drop the task altogether. Helping them get started is helpful but isn’t always useful, as often we don’t know or can’t work out what the next step is.

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5) **Planning and prioritization** - This relies heavily on visual memory and visual memory manipulation. The ability to use imagination to see oneself carrying out tasks or seeing what will be needed during the process of carrying out tasks. For most people, these processes usually operate below the level of consciousness. For those lacking these skills they must be developed at the conscious level before they can become automatic. This is where goal setting is so vital for the SCA survivor.

6) **Shift** - The ability to "Go with the flow". Being able to think and adjust as situations change. As working memory finds it difficult to bring all the functions of memory together, your survivor may find they are rigid in their thinking and find it difficult to adjust to changing situations.

7) **Organization** - Also heavily reliant on visual memory and visual memory manipulation. Using visual memory manipulation one can visualize efficient ways of organizing objects. They can easily lose their train of thought and keeping track of things is difficult.

8) **Self-monitoring** - The ability to assess one's performance by evaluating how they are doing. Weak self-monitoring skills result in surprises when things go wrong or they don’t do as well as they thought they were doing.

For each of the eight executive functions there are exercises that can rebuild your neural networks to make you more capable in each. Again, your physiotherapist should be able to assist, and even your psychologist, as they know
methods to make the mind-body connections so vital in recovery. That’s why having them on your team is so important.

**Getting that brain scan**

As you can see, any damage to the prefrontal cortex is cause for concern, as is any damage to the brain. Ensure you get a CT or an MRI and have the results spelled out for you and your family verbally and in writing by a neuropsychologist and **don’t leave the session** until everyone’s questions have been answered. If this isn’t offered to you (and more often than not it won’t be), then demand it for your own mental health and that of your family. Doctors can be funny about things like this, probably due to the cost, but simply tell them you require this information to assist you in recovery and they tend to fold under the pressure. One SCA survivor even threatened their specialist with a malpractice suit if they didn’t give her a scan. Her doctor immediately relented. You can also go through your GP or PDP to get a scan. Remember, they are doctors, not Gods, and they are no different from anyone else offering you a service. So ensure you get what you need from them if at all possible!
Ch 13  Rules for your mental and physical health

Rule 1.  Join a support group

Most SCA survivors complain that there is little follow up care after discharge from hospital, unlike survivors of heart attacks, strokes and other debilitating diseases. This is slowly being addressed, but to date, follow up care is really up to the survivor and their caregivers to establish once you leave hospital. This is where being a member of a support group and being armed with information is critical. So the sooner you establish your support group and begin your rehab, the better.

I found the Cardiac Arrest Survivors Groups on Facebook to be extremely helpful. They will support you if you’re feeling down or confused, or when something positive has happened and you want to celebrate, or if you have a question that you need help answering, or just generally to let you know you are not alone. They are great at offering advice on what to do, who to see, and on any other topic that relates to your situation. There is nothing better than finding out what you want to know from people who have already been there. They also celebrate what is called your Re-Birthday. This is celebrated at yearly intervals on

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48 Cardiac Arrest Survivors Group on Facebook; www.sca-aware.org; www.startinghearts.org;
the date of your first (and hopefully only) SCA. So celebrate your survival. You’ve already beaten the odds, but always be careful:

“More than 80 percent of Sudden Cardiac Arrest victims who are discharged home from the hospital live at least one year. More than half live up to another five years after resuscitation.” (Dames, 2018).

Also, a myriad of material is online that you can read too - just type in sudden cardiac arrest support in your Google search and you will find heaps. Being armed with as much information as possible is really useful in determining what you need to do to develop your strategy for recovery.

**Rule 2.  Be KIND - to yourself**

This is important as frustration as to where you are physically, mentally and emotionally can take its toll on you and everyone around you. Don’t forget you are not alone in this experience. Your partner, family, friends, workmates, and even your neighbours, are also involved and will feel the impact of your feelings, behaviours and moods. The gambit of emotions run from extreme anger to total placidity with everything in between. Suicidal thoughts and real expressed anger against loved ones is not uncommon. Try to remember that many SCA victims have died and other SCA survivors are kept alive only by machines. So if you're
reading this, consider yourself well ahead of most! But it can get frustrating. Even telling a little story can seem like a train wreck!

Figure 7. Often I lose my ‘train’ of thought.

![What I think I'm like when I tell a story vs. what I'm actually like](image)

Take time to do something you really enjoy everyday. It might be simple like watering the garden, or taking the dog for a walk, or simply playing a game on your phone. But give yourself these times to be at peace. I found that a nap in the afternoon helped in my first few months to battle the fatigue. As I got fitter, the fatigue diminished and I no longer required a nap (most of the time).
If you do something dumb or make a rash decision or forget how to do something, go easy on yourself. This was my biggest problem. If I made an error I would simply beat myself up and try to do it again, and fail again. I felt like a loser. Again, I was simply being too hard on myself. But there is a saying - ‘Practice Makes Perfect’. So I persisted and started to notice I was getting a little bit better with each repetition. Then I remembered from my psychology days that it takes at least 50 repetitions to make something a habit, so I started to keep track. That is how I solved my shoe tying issue - simple repetition until I managed to do it properly one morning. I ran in to call my daughter in NYC (the bossy one) to tell her the news. She was as excited for me as I was. An awesome and unforgettable moment. So take heart in any progress and remember how you eat an elephant….one bite at a time. Be good to yourself with every little bite!

**Fatigue**

Fatigue is a major issue for SCA survivors. You will feel extreme fatigue for some time so learn to deal with it. If you are tired, take a nap or have a rest. Don’t apologise to anyone. Fatigue is a way for your brain to tell you “I need a break. You’re pushing my limits”. Listen to your body. Pushing yourself past the limit is unproductive. My psychologist likened it to a set of stop lights. If you’re feeling good, the light is green. If you are starting to get tired, the light turns yellow and
this is when you need to take caution and stop. When the light turns red and you keep going, what happens? You need to stop otherwise you’re putting yourself and others at risk. You get pulled over and issued a ticket. Same thing with your brain. Go into the red light area and you get punished. Going into the **RED** is counterproductive and will cause you to go backwards, not forwards. You will also tire easily and become grumpy and not in the best of moods. This can rebound on your loved ones and that is not what you want to happen.

**RED** - Stop Immediately. You’ve done too much and this is counterproductive to recovery.

**YELLOW** - Slow down and stop. You are getting beyond the point of no control.

**GREEN** - Go ahead and enjoy yourself, but try and ensure you go the speed limit or you will tire too rapidly.

As a sign in my daughter’s house reads:

“In a world where you can be anything, **be kind**”

Use this as a daily mantra and it will serve you and your family well.
**Rule 3. Being KIND - to your partner and/or caregiver**

**Disengagement**

Often you will feel and be disengaged from your loved ones. They will find this hard to understand but once again, this is a natural function of damage to significant areas of your brain. But remember, you are still someone’s husband/wife, dad/mom, son/daughter, friend or neighbour, and they might not understand where your head is at, so try to always be kind to everyone. They are just trying to support you and be nice and don’t deserve your anger or exclusion. This isn’t always easy as many of us find we disengage from everything (this is a natural result of prefrontal cortex damage\(^{50}\)). Too much stimulation tends to over power our brains and the way the brain deals with this is to shut off to such stimulation and disengage\(^{51}\). You might find crowds or other people extremely taxing and difficult to handle. I know I certainly did. All the noise and so many people made me feel anxious and after a short while I simply became exhausted and then disengaged. I found that just going into a quiet room for 5-10 minutes to rest was all I needed to come right again so I could go out and face the crowd once

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\(^{51}\) Personal communication. (2019) From my personal psychologist from the Taranaki District Health Board.
more. Be careful and particularly mindful over holiday times as they can be especially trying.

This is a very important issue. Quite a few survivors end up losing their partners and/or close friends due to the disengagement and potential anger issues. They claim we don’t listen, or remember anything, or no longer meet their needs. This can all be true, not due to a lack of love or respect for them, but simply as a result of how our brain now works (or doesn’t work).

Others who have had a SCA become very distracted and chronic fatigue is an issue after their SCA, a very common complaint. One woman stated that:

“...when I came home from work every night he [her husband] simply didn’t hear a word I would say. I just wanted him to acknowledge my day, but he just wasn’t there anymore. It was an impossible situation.”

Eventually they split up.

**Being kind to your significant other**

You didn’t ask for this, but you got it anyway, and there is no going back. It’s yours to deal with and being easier on yourself and your partner is vital. Never forget, *they didn’t ask for this either.* It doesn’t give you an excuse to be unkind to anyone else, but it means look closely at yourself:
• identify your shortcomings,
• know what behaviours are not acceptable and refrain from them,
• learn how to deal with unwanted or inappropriate emotions, and
• give yourself a private outlet for the extreme emotions you will feel during your journey forward.

Check this list often and correct your behaviour wherever appropriate. If you're feeling tired just before your partner is coming home from his/her workday, go have a nap or rest just before they get home so you will be fresh and ready to engage with them. If you're feeling angry, go into the other room and deal with it. There are lots of techniques to help you deal with anger. See the following websites for help;

• https://au.reachout.com/articles/8-ways-to-deal-with-anger
• https://www.verywellmind.com/anger-management-strategies-4178870
• https://www.helpguide.org/articles/relationships-communication/anger-management.htm
• https://psychcentral.com/blog/the-7-best-tips-for-handling-anger-and-resentment-in-relationships/
• https://www.apeacefullifecounseling.com/how-to-control-anger/

**Being Eeyore**

There were times during my journey my kids accused me of ‘being Eeyore’ from Winnie the Pooh:
“Oh no. Everything happens to me. I guess I must deserve it. Always me. Oh well. Gotta move on.”

I do a good Eeyore impersonation now. For me, it was simply that I thought my speech had been affected and at times I must have sounded like the old, grisly donkey, and at times I even acted like it. This is where your psychologist will be vital in helping you through these situations. I even had a speech therapist for a while, but she too thought I sounded great so my lessons didn’t last long. Really, it was all in my head and then reflected in my behaviour. It can be a minefield, but with perseverance and help you will make it through. Don’t let anyone accuse you of being Eeyore! No one likes being around a grizzle guts. Remember, you owe them your best you can be at the moment and a promise you will work at getting better, so no more Eeyore.

Figure 8.  *Feeling and sounding like Eeyore!*
**Rule 4. View This Time as a Real Opportunity to ‘Do Over’ You**

Mindfulness, self-improvement, building a new you, and motivational readings and/or courses, can be very useful. Living in the present can be far more rewarding than living in the past. Don’t ever wish you were the ‘you before SCA’. This is a real opportunity to make an even better version of you. Few people ever get a ‘do over’ in life, but this is your chance to improve yourself in any way you want. Don’t squander this unbelievable opportunity. If you view your new life this way, it makes your future much more positive and keeps you forward thinking, rather than looking back on what was but will never be again. So develop this new attitude and you will find you are automatically more kind to yourself as well as those around you who matter.

I found developing this philosophy made me more tolerant and motivated to achieve something with my life (hence this book and website). I also built better relationships with my family, rekindled some with old friends, and made new, constructive friendships. I also adopted a ‘Pay It Forward’ attitude which I found increasingly rewarding.
Rule 5. Recovery is not linear!

This is important for everyone to understand, but especially you. This gem of advice came from my youngest daughter who suffers from a rare disorder that can be pretty debilitating. But she has worked through most issues with a smile and a positive attitude, despite nearly dying several times and countless days in hospital. She has had setbacks, but continues on, recognising that recovery will be going along great for a few days or weeks, then all of a sudden, you're back in pain or you forget how to tie your shoes or you forget your phone or keys. All of this is to be expected of a SCA survivor so don’t get upset when it happens. It is all part of the longer term recovery process, so look at the big picture and don’t micromanage your recovery. Keep an eye on the overall progress and know that setbacks will occur, but you will overcome them in short order and with a positive attitude. For me, they nearly derailed my recovery until my daughter pointed out her philosophy. It was some of the best advice I ever received and I’m happy to pass it on on her behalf. So write a sign…

“Recovery IS NOT Linear”
Put this up on your wall, on your fridge and make it your mantra. It will be of enormous assistance to you and help those around you understand when you’re having an off day.

**Rule 6. Living a healthier lifestyle.**

Make a commitment NOW to live a healthy lifestyle by:

- Eating a diet low in saturated and trans fats, and high in soluble fiber and fruits and vegetables,
- Exercising regularly,
- Getting to a healthy weight and keeping it,
- Managing stress,
- Quitting smoking.

**Diet**

No one likes being told what to eat, but a balanced, healthy diet is an essential element in your road to recovery. We all know that a high cholesterol diet is dangerous, so cut out the processed and fatty meats from your diet, drop the full sugar and energy drinks, and fast food is a definite ‘no-no’. A diet low in saturated and trans fat has been proven to reduce cholesterol and generate a better balance between good and bad cholesterol. This significantly reduces the chance of cardiac disease and that will reduce your chances of another SCA. Read the material on the
package and check for trans fat, saturated fats, sugar and how much each product contains. You will be shocked particularly at the sugar content in just about all products, especially those produced for the USA market. Increase your intake of green and leafy vegetables and you will be on your way to a healthier lifestyle. Learning how to cook healthy meals is beneficial not only for you, but also for the entire family. Just because your food is healthy doesn’t mean the meals can’t be super tasty! Learn how to make these meals and sit down with the family daily to enjoy them.

**Exercise**

Exercise is essential and will make you feel better and give you more energy. Getting fit is, in my opinion, the most important thing you can do. Fitness promotes strong muscles and bones, improves respiratory health, and reduces your risk of type two diabetes. Exercise, coupled with a healthy diet, helps you shed any
extra weight and you will even look younger and feel younger too. It gives you more energy and makes you feel better and it is extremely helpful in battling the fatigue issues you will experience. Targeted exercise also helps generate new neural network pathways that will replace damaged ones due to your SCA. The brain is very forgiving that way. So by doing the proper exercises you can regain your balance, dexterity, muscle coordination, and potentially lose any clumsiness or dexterity issues. And the exercise doesn’t mean you have to turn into a gym bunny! Many are very moderate and simply require repetition to be effective. For example, setting on the floor, raising one leg and writing the alphabet with your foot, then repeating on the other side, is useful for regaining your balance and coordination! Unbelievable, but true!
**Weight**

Getting to a healthy weight is vital if you are to keep from having further heart problems. In America today, over 36% of adults are obese, in Canada that drops to 29%, in Germany 22.3%, in Italy 19.9%, Malaysia at 15.6%, in Thailand it’s 10%, in China 6.2%, Japan it is 4.3%, and in India the obesity rate is 3.9%\(^\text{52}\). While the ‘obesity paradox’ suggests better outcomes from a SCA for obese individuals, it is dependent upon the distribution of extra body mass. If it is centralised around the middle of the body, then your chances of survival drop significantly\(^\text{53}\). So getting fit distributes weight more evenly, exercise and weight loss go hand in hand.

**Stress**

Stress can be a major hindrance to your recovery. Worrying about;

“Will I have another SCA?” or “How long can I live with an ICD?” or “Will I ever regain my ability to go climbing again?” or “How long will it be until I remember what happened?”


Stressing about your condition is totally counterproductive and a real waste of energy. If you have to worry, then throughout your day, when something comes up you want to worry about, write it down then move on. Then, at a specified time, let’s say 7pm, simply pick up your list, look at it, and worry about those things as much as you want for 20 minutes only. After 20 minutes of worrying your head off, you stop. After 7.20pm you can start the process all over again for the next day. This takes away hours you will spend worrying and limits your time to stress. You still get to worry, but now it is controlled. What you will discover is that by the time it comes to worry, many of the items on your list you will almost laugh at. They won’t be the big worry you thought they were when they arose. This is a very effective technique and if you’re a worrier, it will work miracles. It takes dedication and commitment to make this process work, but after about a month it will become a habit and you will find that you actually won’t need this time to worry as you progress. Worrying is a major cause of stress in SCA survivors and it can interfere with not only your life, but have an impact on those around you. So get everyone to practice that little worry technique and everyone will be better for it.
Anxiety

If anxiety gets too bad, talk to your psychiatrist. There are a number of medications that can help. He/she will be able to assist you by prescribing what is right for you. Also, talk to your psychologist as they can assist you as well. Don’t let anxiety get on top of you. It can make you depressed, lethargic, and reduce your enjoyment in life. Get help! And don’t forget, anxiety and stress go hand in hand: the more anxious you are, the greater the stress level, and as the stress level goes up, your anxiety increases. A vicious cycle you must learn to break. Again, there are mindfulness techniques that can help as well as exercise and meditation programmes that can be effective. Whatever you do, break this cycle by whatever means. Your ultimate survival and enjoyment of life depends on it.

Getting good exercise also helps reduce anxiety, so don’t forget to do your exercises and talk to your physiotherapist about things you can do to reduce your anxiety levels. They will be able to offer you a number of simple procedures to follow. This is vital to ensure you reach optimum recovery as excessive anxiety can set you backwards fairly quickly.
Smoking

Stop Smoking! I’m sorry to say that if you are a smoker. But if you want to live longer, then now is the time to quit. A systematic review found that smoking is associated with a 60 percent increased risk of incident heart failure and death.\textsuperscript{54} So if your SCA was caused by heart failure, then your addiction to smoking may be the cause. If you continue smoking after your SCA, then you will further damage the lining of your coronary arteries, restricting blood flow to your heart and priming you for yet another heart attack\textsuperscript{55} or SCA.

Quitting is preferable at any stage of life, but particularly if you are under 40. Already the life expectancy for smokers is at least 10 years shorter than for nonsmokers. Quitting smoking before the age of 40 reduces the risk of dying from smoking-related disease by about 90%.\textsuperscript{56} There are numerous ways and groups that can help you quit. Try the following websites if you want help or more

\textsuperscript{54} Kamimura, D. \textit{et al} (2018) Cigarette Smoking and Incident Heart Failure: Insights From the Jackson Heart Study Circulation 137(24) Retrieved online 29 July 2020 at: https://www.ahajournals.org/doi/10.1161/CIRCULATIONAHA.117.031912


information, or talk to your GP. There are so many ways to stop and you want to find the right one for you;

- https://www.lung.org/quit-smoking/i-want-to-quit/how-to-quit-smoking
- https://www.helpguide.org/articles/addictions/how-to-quit-smoking.htm

There are about a gazillion more websites but at least these will get you started in your quest. Good luck!

Ch 14  My personal journey

Introduction

As important as your physical health is your mental health. Suffering from the effects of a SCA can be a lonely, difficult and lengthy journey. For starters, you don’t remember any of it. You simply remember waking up in a hospital, possibly with tubes down your throat, and not understanding why you're even there or what happened. Confusion is a natural reaction. Your family are there thinking the worst, worried and looking scared. They might even be crying! What the heck is
going on? Not the best start to your day is it! On top of that, you feel rather foggy in your brain and find it difficult to think like you expect. So what’s up?

Then the doctor or nurse comes in and says;

“Gee Mr. Shanahan, you gave us quite a scare.”

Then you ask your son-in-law what happened and he says;

“You died on us Dad. Lucky we happened to be outside Bellevue Hospital or you might not be waking up. In fact, they told me to get the family together as they didn’t expect you to make it through last night.”

You respond;

“Last night? How long have I been in here?”

and he replies;

“Two days. You’ve been unconscious and they only thought you might pull through when you started trying to pull your breathing tube out!”

I’m sure each of you have your own story about when you woke up and what you discovered. Not the best start to your day was it! But it happened, so now welcome to the ‘New Normal’!
The event

So let’s talk first about the event. Most of us believe that we felt just a nothingness, but interestingly it was a very peaceful, restful, nothingness. No pain. Just peace and quiet. There were no bright lights, Pearly Gates, I didn’t even see Elvis, or even the Highway To Hell! Just nothing but a peacefulness that was very pleasant indeed. Was I disappointed? No. In fact, if this is what dying is, then it isn’t half bad. So while I was shocked at this happening to me, it actually wasn’t such an unpleasurable event as one might suspect.

Then I started learning about what had happened to me and I was rather shocked. I coded and it was about four to five minutes before CPR commenced and then three minutes before the trauma unit arrived and got my heart started, but then my heart went into ventricular-fibrillation and it took several shocks and another three minutes to actually get the blood to my brain moving properly. All told, about 13-14 minutes in the Twilight Zone. It wasn’t surprising that they told my son-in-law to get the family together if they wanted to see me one last time. Immediately it was understood that I would undoubtedly have some brain impairment.

57There's no formal definition for a code, but doctors often use the term as slang for a cardiopulmonary arrest happening to a patient in a hospital or clinic.
Discharge

Well, I survived and ended up being discharged just eight days later, much to the surprise of everyone concerned. I could walk relatively well, felt good about myself and my body, was emotionally stable and could perform most tasks asked of me. I did become fatigued fairly rapidly but spent time each day of the following weeks napping and simply believing I was recovering.

Being a dual national and having places to live in both New York City and in New Zealand, we decided I should go back to my permanent home in New Zealand rather than suffer through a New York winter (my SCA was on Oct. 10, 2018). When I got back it was close to Christmas so I waited until the New Year to get my rehab started. In January, I started my rehabilitation and blew through the hospital rehabilitation with no problems. It was primarily for stroke and heart attack patients and for me the tasks were easy and I got through them quickly. However, after being released from the hospital rehab unit I continued having problems with my coordination (walking, eating, using a hammer, etc). It seemed like I was going backwards. Mostly it was simply me trying to do the things I did pre-SCA, and I was found wanting. But be aware that it isn’t uncommon for the full effect of any damage to the central nervous system to not be felt until
sometime after the actual event, even months after. This is what seemingly happened to me and it really got me down. So I demanded a CT scan to find out if my brain had been damaged.

**The CT scan**

In February 2019, I got my CAT scan and the results shocked me. There was damage to my cerebellum and significant damage to my basal ganglia, caudate nucleus (embedded within the basal ganglia), and some to my prefrontal cortex. Recalling my psychology studies many years ago, I realised this wasn’t a good sign. I requested a full explanation as to what issues I could expect and whether or not I could build new neural networks to compensate for the areas that were damaged. The news was both good and not so good. Yes, the plasticity of the brain does mean neural networks can be reformed and even regenerated, BUT, the damaged areas were mostly in the older brain and these are somewhat harder to adjust and remake or rewire. Not that it can’t be done, but there will be no guarantees. Few with damage like this would ever make a full recovery. According to my specialist:

“So if you get 60% back that would be a bonus, 70% would be unbelievable, 80% possible but unlikely, 90-100% not a real possibility.”

58 The Doctor who informed me of the results of my CAT Scan from the Taranaki District Health Board, New Plymouth, New Zealand. February, 2019.
I was stunned. I immediately wanted to prove him wrong and started out working to prove he had underestimated me. After a few really tough months where I continually pushed myself into the red light area and beyond, I realised I couldn’t do this on my own and looked for help. I was actually starting to go backwards.

**Getting the help I needed**

I knew I was getting depressed so I went back to the public health system and got a great psychologist assigned to me, as well as an excellent psychiatrist. The psychiatrist and psychologist diagnosed Post Traumatic Stress Disorder (PTSD) and I was prescribed Venlafaxine. The dose was later increased as I am a fairly big lad and the original dose simply wasn’t doing the trick. I met with my psychologist weekly for a while, then every fortnight and finally once a month.

Enter my physiotherapist. She was brilliant and in one session she set me on an amazing path to recovery. She took me to *CounterPunch* classes at the local boxing gym and these proved very beneficial. This is a special programme for people with Parkinson’s and, as the basal ganglia is the area most affected by Parkinson’s, these classes were right up my alley. I learned how to coordinate my

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59 Effexor XR (Venlafaxine) is a selective serotonin and norepinephrine reuptake inhibitor (SSNRI) type antidepressant.
60 Special thanks to everyone at the Rapara Gym in New Plymouth, New Zealand. Your care and understanding of the needs of your clients was terrific and I am forever grateful to all of you for your help.
left and right hands, how to move my body in a more smooth manner and generally get my walking adjusted so it was better than before. Unfortunately for me, for personal reasons she was leaving the practice and there didn’t appear to be anyone else in the area who could help me. So once again, I was on my own. By Christmas time I was getting a bit depressed. While I performed extremely well on my psychological tests, I knew I wasn’t performing at the level I was before my SCA, and physically I was starting to go backwards. Over Christmas 2019 I was given the name of another physiotherapist and called him. He was awesome as well. He knew exactly what I needed and after only a couple sessions, I was back on track again.

We had by this stage moved from our country place into an apartment in town as the garden and lawns at our country retreat were just too much for me to handle. This added to my depressive mood. But I joined the gym, which was only a short walk away, and by early March 2020, I was once again making good progress, walking my dog, Louie, about 8-9,000 steps everyday on the oceanfront walkway that was just outside our apartment, boxing twice a week, and going to the gym two or three times a week as well. I felt like I was on the upward trajectory again.
**Enter the coronavirus**

Then the coronavirus arrived. We went into complete lockdown for five weeks and then maintained lockdown for the over 65s for a further three weeks - eight weeks at home in total lockdown unable to see my daughters, grandkids, in-laws, friends - no one. This was a real blow. I tried exercising at home with some success, but it simply wasn’t the same and I started to slide backwards again. Later, around June, 2020, after lockdown took its toll on all of us, my dosage of Venlafaxine was increased again by my GP after consultation with my psychiatrist. This helped enormously and I started to feel much better.

**After lockdown**

As we came out of lockdown and back to normal life in New Zealand, I started back to boxing and the gym and walking Louie on the waterfront. Now I’m back in New York for late summer and doing much better. My daughter and son-in-law had some reservations of my coming back as they didn’t want a repeat of the last visit. But I decided to come anyway and although New York City is still pretty much in lockdown, our apartment has a good gym so I can exercise and there are lots of places to walk along the East River when it isn’t too hot. And both of them are great at keeping me motivated. So it’s great to be back in the Big
Apple even though it has changed so much due to the Covid-19 outbreak. So I am now happier, on a better road to recovery, and regenerating those essential neural networks that were damaged and living a much better, healthier and happier life. It has taken 21 months, but I am getting closer to most of my goals and I have accepted that, while I’m probably only maybe 60% back to where I was, I can live with that happily. Better than being in a box and only a memory to my kids and grandkids. And I will continue to improve!

**Summary**

To summarize my journey, it went from shock to disbelief, to reality, then depression, to anger at what has happened to me, then to taking control. Finally I reached a state of acceptance and happiness to be where I am at the moment and grateful for everyday I get as a bonus which provides me an opportunity to contribute to the health and recovery of other SCA survivors.

So where are you on your journey? Have you started yet? Are you getting the help you need? Have you accepted that this is your issue to solve and only you can do it? Yes? Great! Keep going. No? Why not? Take the bull by the horns and no matter how damaged you might be there is always the chance to get better. The brain changes all the time and you can make it change to your advantage. So make
a start. It will be slow at first, but you CAN DO IT! All the very best. And if I can help in any way, send me a message on the website listed in the back of this book and I will do whatever I can to help out.

You have two hands. One to help yourself, the second to help others.

The Journey in New Zealand
For Partners, Caregivers and Family

Ch 15  Don’t expect to understand

If you are a family member or close friend of the SCA Survivor, there are numerous issues you will have to deal with, but Number One is:

*Never expect to understand how they are feeling.*

Take this as a given please. Never say “Oh, I know how you must be feeling” or “I can understand why you feel that way.” Because you don’t understand and will never be able to. Each of us knows we are different and, even if we can’t really put it into words, we definitely know we are not the same person we were before our SCA. That’s all there is to it. It’s like asking someone who’s never had a baby to experience childbirth. This feeling of being different is ours to deal with and no one else can help us on that journey to discovery (should we decide to take it). This is the most difficult thing for many of us, and you, to deal with. We might look the same, talk the same, even, if you’re lucky, sound and walk the same. We are still someone's husband/wife, father/mother, brother/sister, grandparent, uncle/aunt, nephew/niece, friend or workmate, but something inside of us has changed as a result of our SCA and we are not the same person you knew before. We have been to the other side and returned, and I guess that changes us
somehow. I don’t know the answer for sure, but just about every one of us will tell you that we are somehow different than we were before. So please, just accept it and help us move forward, and when we surprise you with a rash decision, or outburst of unexplained angst, or suffer from irrational behaviours, or wake up at 1 a.m. from a nightmare, or forget what you just asked us to do, just give us comfort. That’s all we need. Please don’t ask us why something happened or how we feel about things. Know that we still love you, but we have a lot of inner turmoil to deal with so sometimes we might not show it like we used to. Apologies for that, but let’s move on. Be strong and confident in our feelings for you and yours for us and we will do just fine.

_Frustration_

The frustration we can all feel can be epic! Imagine one day you are a high achiever, a master of DIY, a superb gardener, an academic, or a wonderful grandfather and all of a sudden you don’t feel even close to meeting what the ‘old’ you could do. You don’t feel as intelligent, as capable, as sociable or as loving as you used to. That is like being hit in the head with a baseball bat! Ouch. But that is likely how your SCA survivor is feeling when they come home from hospital, if not immediately, then after the impact of the SCA starts to be felt. I think there
might be a short-term high where we live on adrenalin for a few days (or even longer) due to the fact that we are euphoric to have survived the unsurvivable and be going home. There is also some scientific evidence to support the argument that the full impact of the lack of oxygen to the brain isn’t fully felt or recognised until sometime after discharge from the hospital\textsuperscript{61}. This certainly was my experience. Whatever the reason, the reality of what you can and can’t do any longer starts to settle in. For me it started with my eating and shoe tying. Both caused me enormous angst and I tried to hide it from my partner and everyone else. But the inability to even tie my own shoes was embarrassing. I even went online and took a tutorial on how to do it. It took me a fair while but I finally re-learnt to tie my own shoes. But I still, even after all this time, have problems doing it properly and have to really think about every movement and I still tend to fall towards the left every time!

I also had to get used to coordinating a knife and fork again. I couldn't get my left hand to do what it needed to do to get the fork or spoon properly situated and to my mouth without incident! Talk about embarrassing. Well, it was for me anyway. And I’m left-handed! It took many months of practice to eat a meal

\textsuperscript{61} Michaud, M. (2015) Understanding the ‘Enemy Within’ that Causes Brain Damage after Cardiac Arrest
Newsroom University of rochester Medical Center Retrieved online 3 Aug 2020 at: https://www.urmc.rochester.edu/news/story/understanding-the-enemy-within-that-causes-brain-damage-after-cardiac-arrest
without having it all down the front of me or on the floor (which made Louie, our old Bichon, very happy!). In fact, I still have issues with eating, but I am better and don’t get as embarrassed as I used to. That is partly because my partner was really understanding and now we pretty much laugh if I have a spill or drop food on myself or the floor. If you didn’t laugh, you would probably cry. So be prepared for the little things to cause major frustration for your SCA survivor and for you. And learn to laugh at the little mishaps. I have found laughing at myself and having my partner join in when I screw up is really good mentally and keeps me from getting as upset with myself as I used to. It might just have even brought us closer together during this trying time. But just be aware of one another’s frustrations and let the survivor try themselves to do things you know may end in disaster. Just by trying, they are making new neural networks and they might just surprise you one day!

*Push them gently to do more and don’t ‘mollycoddle’ them*

Whatever you do, don’t do things for them they can do for themselves. They have to take responsibility for their own recovery. This can be tough as you watch them struggle to get out of bed, or walk down the steps, or move themselves away from the table after dinner. But if they can do it, let them. And if they can’t do it,
ask them to at least try! If they can’t, then help them. But the only way the neural networks can be rewired is by doing something, then practicing that movement ad nauseum! If you do it for them, they will start being dependent upon you and are likely to not progress as rapidly or even at all. Yes, there are times when a comforting hug is appreciated, but just don’t go doing tasks for them that they can do themselves.

*Set goals and celebrate each little achievement*

Work with your loved one to set simple little goals. To start with, make them small and relatively easy for them to achieve. Cutting their own nails, cooking a meal, doing the dishes, planting the flowers, even just watering the lawn or reading a children's book to one of the grandkids! The goals need to be dependent on the level of brain injury and what your partner/friend can actually do and used to like doing. But be careful. If they were a great DIYer, it might not be good to put them in charge of a chainsaw or power tool just at the moment! I hit myself on the thumb with the hammer several times and my partner finally said enough, took the hammer from me and did the hammering herself! We both had a laugh about it afterwards and my DIY days are more than likely at an end I think.

Put these goals in writing and set them up somewhere where everyone, particularly the survivor, can see them daily. Write them up in simple terms but
ensure they are stated clearly and have a goal date and are easily achievable. Once they start knocking off the goals, celebrate them! I don’t mean have a big party and invite all the neighbourhood around just because your husband cooked a decent meal (although that could be a reason for some families), but a simple;

“Wow! Well done. That’s something you couldn’t do before. Good job honey. Keep it up!”

That’s really all we need and believe me, we will feel proud as punch!

After the first set of goals are achieved, start on a new set, then start extending them to be slightly more long term. Things like:

- “I will lose five pounds before Christmas.”
- “I am going to walk around the mall at Christmas and see all the decorations and buy you a present.”
- “I will get my driver’s license back by June.”. §62

Then work out what smaller goals they must achieve to reach each of these bigger goals. Write them out in order of ‘need to accomplish’ and then let them get started. This is great for keeping them on track and when they knock off the first big one, then it is time to celebrate with the family! Goal setting with your partner

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§62 In many countries it is usual for a SCA survivor to forfeit their driver’s license to at least 6 months and in some countries you will be required to sit a driving test to get it back.
may be *the most significant* thing you can do to help them. As the old Scottish saying goes:

“If you don’t know where you're going, then any road will get you there!”

Make certain you both know where the road is leading and how you intend on getting there. This goals map will serve you both when times get tough, and, believe me, there will be hard times ahead.

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**Ch 16  Give them time and space to grieve**

Your loved one or friend has just undergone a major trauma (as have you). Imagine waking up and being told you were dead for X amount of time and were brought back to life. You’re so lucky, as only a small percentage ever make it.

WOW! Jubilation, joy, wonderment, then:

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63 Carroll, L. Real name Dodgson, Charles. (June, 1865) Quote attributed to the Cheshire Cat in *Alice in Wonderland*

Why me?

I’m not the same.

What? I have brain damage!

Oh no, my physical side has problems too.

Great, what a sorry state I’m in.

Maybe I would have been better off not being revived.

Damn, this is just too hard.

Okay, if this is as good as it gets, then I'll take it.

Wow, I’m starting to get a bit better!

This is awesome!

I’ll take this.

This is a common progression for many of us and it reflects the stages of grieving outlined below. Remember this grief is real and you will probably be going through these stages as well.

*How grief affects your brain*

How does grief affect the brain? The emotions you experience after a SCA look similar to grief and underneath that grief are neurological changes that take place in the brain. These involve emotional regulation, memory, multi-tasking, organization, and learning (all those things supposedly controlled by your basal
ganglia and prefrontal cortex). When you're grieving, a flood of neurochemicals and hormones dance around in your head. These aren’t always easy to control, so be prepared to give your loved one time to adjust. This will happen to you as well, so be prepared and learn as much about grief as possible to help you through this experience. Many who have witnessed a loved one die and then come back often suffer from Post Traumatic Stress Disorder (PTSD) and getting mental assistance from a trained psychologist is really important. You have a long journey ahead and you will need all the help you can get. Talk to your primary doctor about getting a referral to your local hospital or mental health provider. In many countries, you are likely to get some free visits.

**The six stages of grief**

The six emotional stages of grief are usually understood to be shock/disbelief, denial, guilt, anger, depression, and acceptance/hope. Symptoms of grief can be emotional, physical, social, or religious in nature. Many people do not experience the stages of grief in the order listed above, which is perfectly okay and normal. The key to understanding the stages is not to feel like you must go through every one of them, or in this precise order\(^6^4\).

**Shock/Disbelief**

Obviously all SCA survivors suffer from the shock or disbelief of what has happened to them. Dying and being brought back to the land of the living isn’t something that happens to many of us. Also, the shock of waking in hospital with no knowledge or memory of what happened can be rather distressing. Or getting a phone call in the middle of the night saying your loved one has died but been resuscitated and you need to come into the hospital as quickly as possible. Problematic? Anxiety producing? Obviously, as I’m sure you can imagine. This is also dependent upon the amount of neurological damage your loved one has suffered too. So give them time to adjust to what has happened and help them move forward. The shock and disbelief wears off fairly rapidly and then denial sets in.

**Denial**

Denial is probably less intensive for many of us, as the relief of surviving may be stronger. You may be the one who goes through this stage. “This can’t be happening” or “This is a nightmare” are genuine feelings from those whose partner or friend has suffered a SCA. But equally, the SCA survivor may be in the same space. Denial is a common defense mechanism that buffers the immediate shock of
the loss, numbing us to our emotions. We block out the words and hide from the facts Clarke (2020). Denial assists us in dealing with the emotional pain of loss;

“Denial is not only an attempt to pretend that the loss does not exist. We are also trying to absorb and understand what is happening.”

Often it can take time to adjust your new reality, so give it time! Look after yourself and your other loved ones who could also be facing the denial stage.

**Guilt**

Guilt at letting people down, always feeling fatigued, not being the same person you were, being disengaged from everyone, feeling isolated and wondering “Why me?” are all natural to the SCA sufferer. *Self-blame* usually refers to making self-attributions about the cause of the SCA and goes hand in hand with *regret* which has been identified as involving painful thoughts and feelings about past actions and how one could have achieved a better outcome, as well as feelings associated with unfinished business. Regret is probably the most difficult to deal with as you start to realise you are not the same individual you were pre-SCA and that you have limited capabilities (no matter how big or small) that interfere with

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your life in a myriad of ways. There is some suggestion that there is a correlation between high levels of regret and depression, so keep an eye on your SCA survivor and get them psychological help if you think they are becoming depressed or suffering from PTSD. Both depression and PTSD can be debilitating so don’t let your loved one, or you, suffer needlessly. A psychiatrist can prescribe medications to improve depression or mitigate the effects of PTSD and make life much easier to handle during this difficult period. There is plenty of time after you have an outcome for your survivor or you to discuss coming off the drugs, but in the short to medium term, don't be afraid to utilise them to your advantage.

**Anger**

Anger tends to be the first thing we feel when we start to release emotions related to loss. This can leave you feeling isolated in your experience and perceived as unapproachable by others in moments when we could benefit from comfort, connection, and reassurance. Anger, in itself, isn't necessarily a problem in that it can alert us about things we may need to adjust in our lives, but uncontrolled anger is a different issue. One person reported on their husband, a SCA survivors, that he was just super angry all the time. He had major cognitive

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issues and nothing seemed to get him to respond the way he wanted to respond. This was very difficult for her to deal with. I suggested she get her dad psychiatric help and she eventually did. The right drugs got her father on an even keel and last I heard he was making progress in recovery. So don’t let anger fester. Anger and stress feed off one another. The more angry I get the more stress I feel and the more stress I feel the angrier I get. So get them help as soon as possible for everyone’s sake. Anger can quickly push friends and family members away and that is not what you or the survivor want. Remember, you are only trying to support them and you do not deserve anyone’s anger for doing so. So stand up for yourself calmly and intelligently. Read the literature already mentioned in the section for the survivor and get to those websites and online support. Every bit helps.

*Depression*

There comes a time when our imaginations calm down and we slowly start to look at the reality of our present situation. As our panic begins to subside, the emotional fog begins to clear and the loss feels more present and unavoidable. In those moments, we tend to pull inward as the sadness grows. We might find
ourselves retreating, being less sociable, and reaching out less to others about what we are going through.\textsuperscript{68}

The symptoms of depression—technically referred to as \textit{major depressive disorder}—are characterized by an overwhelming feeling of sadness, isolation, and despair that lasts two weeks or longer at a time. Depression isn’t just an occasional feeling of being sad or lonely, like most people experience from time to time. Instead, a person who has depression feels like they’ve sunk into a deep, dark hole with no way out and no hope for things ever changing.\textsuperscript{69} The only way to get through depression is with proper help via a trained psychologist. So set up the appointments for your partner and you and take them. You might even ask them and the psychologist if you can sit in on all of the sessions. It is vital you get your SCA sufferer and/or yourself help with depression or they can become suicidal and possibly harmful to themselves/yourself or others. So that is why it is so important to have a psychologist and psychiatrist on your team.


Acceptance

When we come to a place of acceptance, it is not that we no longer feel the pain of loss, but we are no longer resisting the reality of our situation and we are not struggling to make it something different. We accept where we are and what has happened to us. It doesn’t mean that we are happy about it or are prepared to live with things the way they are currently. But we have accepted our problems as well as the positives that have come out of our SCA, and there are positives. For example, the opportunity to remake one’s self into a better person is a real positive. Also, getting fitter and losing weight is another positive. So not everything is doom and gloom. But those things come after you accept the position you are in as a SCA survivor or family member and how lucky they have been to even be alive. Acceptance is a liberating feeling and will set you up for a proper future with your loved one and potentially further recovery. Not everyone gets to this stage, but with your help and following the Rules outlined in Chapter 11, there is a much better chance of them making it to this final stage. Make sure you pat yourself on the back and treat yourself bigtime once you reach this stage!
Some final tips

Here are 7 tips to help you, the caregiver during this time:

- If you are mourning for the SCA survivor, make sure to make time for feeling the emotions that arise, whether they are anger, sadness, or pain. There is no need to judge these emotions as good or bad and know that it is okay to feel these and they will not last forever, as all things come and go. You may even create a little ritual where you spend time with a picture or object connected to that person.
- Friends sometimes get uncomfortable around grief and may try to make you feel better in the moment. Thank them for this, and let them know it is normal and natural to feel how you feel.
- Make sure to also take care of yourself during this time, go out on a walk, make sure to eat healthy. Do something everyday just for you.
- Try and open your eyes to the delights around you. It could be a smile on a child’s face or your own. Smelling a wonderful flower or maybe tasting your own favorite food. Even in the midst of grief we can be open to the wonders of life.
- Know your limits and allow yourself to take a break from feeling when it’s becoming overwhelming, but make sure to let your grief know that you will come back. Make a time to revisit it, otherwise it will occupy you all day.

Being altruistic can be a great way to move through grief. Maybe you would like to volunteer at a homeless shelter or make some things for those you care about.

Support has been known to be very helpful and so joining a grief or support group either online or in person can be enormously supportive.

More than anything, treat yourself with love and kindness during this time. The grief will seem more acute during some times and more subtle during others. Know deeply that “this too shall pass.”

Here are a few tips to keep in mind when helping your SCA survivor:

- **Avoid rescuing or fixing.** Remember, the person who is grieving does not need to be fixed. In an attempt to be helpful, we may offer uplifting, hopeful comments, or even humor, to try to ease their pain. Although the intention is good, this approach can leave people feeling as if their pain is not seen, heard, or valid.

- **Don't force it.** We may want so badly to help and for the person to feel better, so we believe that nudging them to talk and process their emotions before they're truly ready will help them faster. This is not necessarily true, and it can actually be an obstacle to their healing, particularly for men.

- **Make yourself accessible.** Offer space for people to grieve. This lets the person know we’re available when they're ready. We can invite them to talk with us, but remember to provide understanding and validation if
they are not ready just yet. Remind them that you’re there and not to hesitate to come to you.

- Read the section in the survivors section about recovery not being linear (Chapter 11, Rule 5) and try to always remember this. There will be ups as well as downs and you will never know when either is approaching. So be thoughtful, watchful and roll with the punches. I know, easier said than done, but at least try!

Ch 17  Patience, it takes time

The ‘new normal’

For most of you, as well as us survivors, there is a hurry to get our lives back to normal, but there is no longer a normal as we used to know it. I remember as a survivor of several devastating earthquakes in 2010 and 2011, we all talked about the ‘new normal’. That term surfaced again during the coronavirus pandemic of 2020. It simply meant we would or could never go back to the normal before the major event and from here on forward things will be different. So you've already had experience with the concept, but now you really need to learn how to live it. Nothing, and I mean nothing, will ever be the way it was pre-SCA, for you, the SCA survivor, your family or your friends. I know that is a big call on my part, but I believe it to be absolutely true. This is particularly evident if your survivor
suffered any kind of significant brain damage. So be patient and learn to live a different and even better life. Cook healthier meals, take more exercise, learn to listen with your whole being and make people feel special and valued every single day.

**Quality of life**

For your SCA survivor, time isn’t necessarily on their side. Close to half won’t get another five years of life and for some it may be significantly compromised. Others may live beyond the five years, but their quality of life may not be what you or they had hoped. But for many of us, there seems to be a stage at around three years where optimum recovery has occurred, then it tends to slow after that, or even stop. After about three years you need to realise that things probably aren’t going to change much more unless new medical technological breakthroughs happen in neuroscience, and these are always possible! There is some evidence that the outcome for a severe anoxic brain injury may be poorer than for a traumatic brain injury of equivalent severity, as assessed by the Glasgow Coma Scale (GCS)\(^1\). In anoxic brain injury, the actual nerve cell bodies themselves

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\(^1\) Anoxic brain injury - treatment and recovery *Headway*, the brain injury association in the UK Retrieved online 2 Aug 2020 at:
are very vulnerable to damage and this damage is irreparable. This is why over half the SCA survivors don’t make a full recovery even after three years (see Figure 9). However, not a lot of money seems to go into brain regeneration research compared to cancer, diabetes, heart disease, obesity, or other deserving illnesses. But I hope this will change as more and more of us make noise and demand better help for all of us who suffer from a SCA. The individual, their partner, their family, and their friends all suffer this debilitating event together and in far too much silence. Let us hope that in the future more emphasis will be placed on finding solutions to regenerating these damaged/destroyed brain cells and anoxic brain injury will no longer be a lasting problem for SCA sufferers. It is time to find solutions, not *shrug our shoulders*.

**Figure 9. Pie chart of expected recovery times for SCA survivors.**

![Pie chart of expected recovery times for SCA survivors](image)

![Pie chart of expected recovery times for SCA survivors](image)
For the Extended Family and Friends

Ch 18  Everyone involved

Who suffers from a SCA

EVERYONE suffers from a SCA, not just the survivor. For a close knit family this can be a devastating event. From the partner of the SCA sufferer to the children, grandchildren, parents, brothers, sisters, in-laws, friends and workmates, a SCA can have tumultuous ramifications. So be aware you won’t be alone in this emotional, difficult, yet remarkable journey. For further insight, go to the SCA Survivors Facebook page and sign up. Then ask for help. You will be stunned at the response! Do it now!

Get everyone involved

Ask everyone to join you in a discussion about what each can do to assist your loved one to recover from their SCA and set up a meeting early on with everyone. Working with everyone in a collaborative manner will make it possible for your loved one to move forward faster and for you, as caregiver, to ensure you can keep them on track. A collaborative effort will reduce your stress tremendously and involving everyone will make your loved one feel like everyone really cares
about them and acknowledges their efforts at getting better. It is a ‘WIN-WIN’ scenario for all concerned.

**The medical team**

Don’t forget the medical team involved in the recovery of your loved one. While they are busy people, they may be able to attend an evening meeting to explain things to the group or even to take part in the proceedings. Never leave them out of the invitations. You never know, they might surprise you and just show up! Wouldn’t that be wonderful.
A loved one suffering from a SCA can be devastating on different people.

The partner

The partner of a SCA victim may be the most affected but they aren’t the only family affected. A partner may face a myriad of practical and emotional burdens, such as:

“What now? How am I gonna cope with this? Can our relationship continue under these circumstances? What impact is it going to have on us? What about his/her parents? How are the children going to take this? How do I tell her/his friends? What about her/his job? Will he/she be able to go back to work? How are we going to pay the bills? And the medical bills? Will we be able to get medical insurance if he/she has to quit their job?”

Remember, it’s the ‘new normal!’ You will have to make adjustments to your own lifestyle to work with your partner and family. But remember this is a collaborative effort to assist your loved one recover as much of their mental and physical capacity as is possible. By working collaboratively, it is a win-win scenario. If you look at it as a compromise, you will soon become disillusioned and
possibly resentful at all the changes you have had to make just for them, and this is
destructive to any relationship. So collaboration is the way forward.

This website\textsuperscript{72} offers an excellent step-by-step guide to setting up a
collaborative effort to help your loved one by involving everyone in the process
and negotiating processes that everyone agrees upon as the best solutions to
assisting the survivor achieve their best possible outcomes.

As 65\% of SCAs outside the hospital happen at home, it is likely you were
there at the time of the event. You may have been the one to start CPR and call for
emergency services. The stress on you will be incredible! You are definitely a
candidate for PTSD. If you feel you need help, ensure you get it. Don’t ever be
afraid to ask your doctor for assistance. They can recommend possible drugs to
assist, or refer you to a psychologist or psychiatrist. If you are planning to assist
your loved one with recovery, then you will need to be on your toes. So get help if
you think you need it. There is no Superwoman or Superman. Don’t try to be one
as this will be counterproductive for everyone involved.

\textsuperscript{72} Six steps to a win-win result. (No Date). 7 Criteria to achieve a winning result. Coaching Retrieved online 2
August 2020 at: http://pagehanify.com/7criteria/coaching/six-steps-to-a-win-win-result/
The children and grandchildren

The impact on the children and grandchildren is just as significant as it is on the survivor or partner. They may be concerned about:

“What happened to dad/mom? Did they really die? Why did they come back? What was it like? Will they still love me like they used too? Will they die again or are they okay now? I don’t understand what’s going on! I don’t want my dad/mom sick, it’s not fair! I’m scared! I don’t want mom/dad to leave me, ever! Will we be Okay? They’re not going away are they?”

The kids and grandchildren may experience nightmares, sleep problems and other stress and emotional issues that will need attending. This can be a terrifying experience for them every bit as much as it is for you. They may also need counseling and help in overcoming the issues associated with a loved one’s SCA. Tell their school and teachers what has happened and ask them to look out for any changes in mood or behaviour. They can be of great assistance.

Try to ensure the children get time with their affected parent, but limit the visits so the SCA sufferer doesn’t overdue it. Getting worn out is actually counterproductive to recovery, as I learned very early on. Wearing yourself out doesn't make it easier to establish the neural pathways you so desperately seek. In
fact, it makes the process that much more difficult. So limit time with kids and grandkids to ensure no one finds it too taxing.

Parents and In-laws

Parents and in-laws are affected too:

“I can’t believe she/he really died! What have they put next to his/her heart? Will it keep them alive for years or just give them a little more time? Why is she/he so disengaged when we come to visit? What can we do to help? My poor girl/boy—why him/her? What did they do to deserve this? Did we do something wrong as parents to cause this? This never should have happened to my baby.”

No parent should have to see their child die, I don’t care if they are brought back to life. It will never be the same again for them or you. They too may require assistance in recovering from the shock of their son or daughter having died and being brought back to life again. Often, religious beliefs can be a source of conflict
with older parents, in particular and their inability to adjust to the fact their son/daughter died and returned. They will need to deal with this and talk to their religious leader for guidance. Ask them to be patient and accepting. This isn’t easy for anyone so their support in the recovery process would be greatly appreciated. Discuss what they can do to help and work forward from there during the collaboration meetings. You will need all the help you can get, and, even if it’s the father coming around to mow the lawns occasionally, or your mum coming over to fold the laundry, every little bit helps. So talk to them about what they can help with and take their love and generosity.

Friends

As for friends, they sometimes withdraw, particularly if they witnessed the event. They often suffer from PTSD and seeing the survivor regularly can trigger
flashbacks of those moments when they were lying there dead. If they performed CPR, it will have a lasting impact on them. Friends are often a similar age as the SCA victim, so they often think ‘There, but for the Grace of God, go I’. All of a sudden they are faced with their own mortality.

If they didn’t witness the SCA they may be put off by the survivor’s sudden changes in mood or their disengagement might be seen as rudeness or not caring any longer. Lots of people have abandoned SCA sufferers due to these and other emotional issues. Try to get them to read this book so they get a better understanding of what to expect and how everyone’s lives, including theirs, has changed as a result of this SCA and involve them in the collaborative sessions.

Real friends will stick by you both, so don’t worry too much if the casual ones tend to slip away. It is a reflection on them, not on you. Remember, they were your friend and sticking by them can make one heck of a difference to their recovery. Just having someone to talk to and remember the ‘good old days’ can be highly therapeutic, even if those good old days were only a few months ago. Remember too that their short term memory has most likely been significantly affected and their long-term memory might not function as it should either. Simply accept them as they now are. They are still your friend and, even when they disengage, don’t take it personally. They can’t help it. Think of these times as a
chance for their brain to digest what has happened and heal. Don’t be offended. And be patient. Treat them like you would like them to treat you if the situation were reversed. Don’t talk down to them or be patronising. They didn’t revert back to 10 years old, they simply have some damage to their brain that is interrupting their current levels of ability. Stick with them and talk about the future. You will all be rewarded in the end. Remember the ‘Pay it Forward’ principle.

**The employer and workmates**

This can be a difficult situation for everyone concerned. Hopefully the workplace insurance will cover the medical costs and the employer may keep the job open for a period of time, but perhaps not indefinitely. See if you can work out a continuance of their medical insurance. There are schemes to assist the family financially if the SCA sufferer is unable to go back to work or requires special care, but these seldom cover the full costs to you or your family. So be aware this is a possibility you may need to face later on. As an employer, talk to the family and explain what options you can offer them to help protect their future. As a good employer, you will want to do everything possible to aid the recovery of your employee, so give them the time they need to find out if they will ever be able to return. Be generous and Pay It Forward by offering a month paid leave to help
them set up his/her recovery with a possible return to work sometime in the next six months. Hold their job open for that time. Allow them to use their sick leave and holidays after that and many institutions have allowed fellow employees to give some of their sick leave or holidays to the SCA survivor to use as well. This is a great effort and sacrifice on their behalf and a way they can Pay It forward as well.

As a partner to the SCA survivor, ask the employer to visit their employee if/when they have time. Do the same with workmates, but caution them that they can't spend too long at the moment as the survivor gets fatigued very quickly. I'm sure they will benefit from reading this book as well, as they will be better equipped to meet his/her needs if they are aware of what everyone is going through. In addition, get the employer on the Team who will meet regularly to devise a collaborative approach to the patients recovery. By having them involved, they have a vested interest in the survivors success and are more likely to keep them on or pay them benefits if at all possible.
Ch 20  Suggestions for post-SCA care

According to Sawyer, et al. (2020),

“SCA survivors represent a heterogeneous group of patients, often with unique and complex needs that are inadequately addressed by current treatment recommendations.”

The few recommendations that do exist for follow-up after SCA are generally borrowed from other specialties for secondary prevention of cardiac events; e.g., placement of an ICD, need for coronary intervention (stenting), coronary artery bypass surgery, or other procedures that will assist the patient in their physical, cardio recovery. These procedures however do not address the enormous number of SCAs that are not cardiovascular related and considered idiopathic. These interventions also do not take into account the psychological needs of a SCA survivor; eg, cognitive, psychological, emotional, social or the needs of significant others involved with that patient who also have been traumatized by the SCA and suffer issues related to such a major life changing event. In the absence of structured care plans or support groups73 (some do exist in the US), informal communities of survivors have coalesced to discuss shared experiences and to assist with navigating survivorship. This is hardly best practice medically, yet it

does raise some interesting questions that show just how left out in the cold SCA survivors and their loved ones are. All they seek is what every other major illness receives: a structured post-discharge care plan for them and their families.

As the number of people surviving SCA increases, this is not an advantageous position for survivors, loved ones and caregivers.

“A lack of uniform patient-centered assessment and reliable provision of resources for SCA survivors after initial medical stabilization perpetuates a fragmented approach to hospital discharge planning. Resources for physical, cognitive, emotional, and social needs are not standardized.”

(Sawyer, 2020)

Being discharged from hospital with little, if any, structured follow up is far from conducive to proper recovery. We need to do better. Some of the suggestions in this book could be considered for implementation by hospitals, health services and health providers to better service the needs of SCA survivors and their families, friends, caregivers and even healthcare professionals who have been involved. Of particular note is the team of professionals a SCA survivor requires to make progress with their recovery, as well as how their SCA impacts on those around them and how to work collaboratively to achieve the best possible outcomes.
In addition, there is no structured material to send SCA patients home with after discharge and doctors usually just wish them well as they depart! Almost every other major health event (transplants, cancer recovery, diabetes, cardiac events, chronic inflammatory lung disease, Crohn's disease, Parkinson’s, Alzhiemers, substance abuse or addiction, sexual dysfunction, obesity) all have follow up care plans for the patient and often those involved with the patient. But for SCA survivors and their families, there is very little specific, if any, follow up and assistance. Someone needs to champion this cause as it is unacceptable to send people home to basically suffer with the physical and emotional scars suffered after a SCA. It is also unethical to allow families and caregivers to suffer alongside their loved one. I speak from experience, but don’t just take it from me. Here are other people’s real comments for the SCA Survivors group on Facebook.

**Responses to post-SCA care**

*Thank you for the warm welcome - new around here. My partner had a SCA, we're 7 months out now and thankfully he's a survivor. As the person doing the CPR (pulseless x 54 minutes) I'm working through a lot of mental health stuff, but part of what I'm struggling with is zero diagnosis. He's had extensive work ups and yet we still have no explanation, which is making my anxiety worse by not having any sort of prognostic information. My question is, has anyone else gone through this and experienced a SCA without reasonable explanation? How did you cope with the "unknown"?*

*Brutal consultation with my EP. I want to understand how my ICD detects and treats. My EP says drink coconut water and he guarantees I won't have another VFIB - My electrolytes have always tested normal - but he's an expert. I know he's wrong - He didn't*
even look at my latest EGM and I had to tell him my genetic test results (HE ordered them and NEVER reviewed!) Then he told me I have long QT - when asked how he concluded, OH because most people with idiopathic VFIB have LQT. WHAT? My ECG doesn't show Long QT, my Genetic Testing doesn't show it, but MOST people.... so that's my highly trained and knowledgeable expert. I want to find an expert in the medtronic ICD that will walk through my data and make adjustments to settings that make sense!!!

How long til y'all felt normal after your SCA? I'm really struggling with energy levels and feeling lightheaded. I can barely walk through Walmart without feeling like I want to pass out. I have to go back to work next month and I'm also in nursing school starting back up at the end of August. I just don't know how I'm going to do it.

Almost three years since it happened. My wife (and lifesaver) and I are still screwed up in the head about all of this. So the cardiologist has referred us to "behavioural health" and I got the letter in the mail asking me to call and make an appointment, but I'm having trouble picking up the phone. I've never really aired such personal stuff with strangers, don't really know if I can talk about it to anyone. My SCA happened during a rather personal situation, which has added to the stress and trauma for both of us.

Next month it will be 3 years since my Idiopathic SCA. I received CPR quickly and b/c of God’s Grace I was shocked quickly by police officers that were on my corner when the 911 call went through. I had Arctic Sun protocol and was kept in a coma for 3 days. Came out of the coma unable to sit up on my own, or speak and with repetitive motions classified as seizures. Had a very difficult time processing the drugs. Had crazy hallucinations, unable to sleep and given the label “ Altered Mental Status “. BTW it took me 2 years to figure out it was the drugs. I had no memory of any of this time and doctors shrugged when I asked about it.

I had mine on November 6, 2018. It took months to get a real diagnosis and answers. It was a banner year as my husband of 9 years walked out on me 9 months later and the company I worked for, basically pushed me out...I've been working damn hard to try and regain some sense of normalcy and doing EMDR has helped a lot....I should add that while I am incredibly grateful to have survived some unbelievable odds, I still have some tough days...this pandemic and being high risk, managing a new job, 7 year old twins and an impending divorce doesn't make it easy and at times I feel like I've been living a bad Lifetime movie!

Was anyone else put into "Induced therapeutic hypothermia" after their SCA and notice that you can't handle heat anymore and even with the AC being on it's still hot to you?
People around you are complaining it’s cold and you don’t feel cold but physically your feet are icicles.

My surgery for a Biventricular ICD is Friday. DOES ANYONE HAVE THIS?? I never got a 2nd opinion. I’m at 32% If I was at 35% I might not be doing this. I just read that the doctors get paid more putting in ICD’s than treating with just meds. I have new symptoms. My feet and wrist are swelling. I had to take my 1st nytro ystrdy. The pain Woke me up. So I’m torn.

My husband has had a defibrillator fitted and isn’t sure if he has to cover up the area it was fitted, in his chest, when sitting in the sun - that’s when the sun comes out in Scotland?

Have any of you attempted to get a massage? I need one so bad on my back and neck and there are a few things in the way as I lay down..the defibrillator being one of them. I think that might be very uncomfortable and so then, why the massage? What did you do to cushion the device, if you did. Thank you.

My sleep has been permanently altered post-event. I think mine is related to changes in my brain function. I don’t wake up thinking about it - I just wake up frequently during the night. Naps solve the problem. I just accept it as the new normal and do the best I can with accepting the changes.

I have major issues with proper sleep patterns. I wake multiple times at night, occasionally with a panic attack over absolutely nothing! Sometimes I feel like my toes are hooked together and this really upsets me and I can’t get to sleep until they are ‘undone’. Ridiculous, I know. But still very real to me. Why is this happening? I can also get very claustrophobic with the covers on the bed. This wakes me up sweating and can induce a panic attack if I’m not careful. I take medication for panic and anxiety, but it doesn’t always stop them from occurring. What can I do? Does anyone else suffer from silly things like this/ I feel such a dork!

Got a new doctor and this one actually believes in medicine. In the last almost 2 years I haven’t been able to sleep until last night. He prescribed me some sleeping pills and they worked. Slept all night, woke up early and feel great.

Weight loss.... so I was in the hospital for 16 days post SCA. I lost about 20 pounds. Since release I have continued and lost another 8 pounds or so. I was not overweight to begin with. Now I feel like I am becoming a scarecrow. I suspect a large part of that is all the
fat I cut from my diet. I also do not seem to have a huge appetite like I used to. Is this normal? What to do to stop the loss? I don't care to retain the lost weight, but it is getting ridiculous.

Can I get medical/life insurance after having a SCA?

I was ONLY able to get life insurance through work when they changed something in the basic underlying policy and declared an "open season" and had to take any employee regardless of pre-existing conditions.

None lol. I’m 39 and can only get the basic offered through my work. Anything with a physical I’m declined.

I've tried a few times, with different companies and even through my own bank. I've always been denied. I have a CHD too.

I have through work and took out the extra plan and if I leave I can continue it no matter what.

Can I get travel insurance if I want to go overseas after a SCA?

Most companies won’t offer you travel insurance if you haven’t been stable for a minimum of one year. But in the case of a SCA, many have been turned down completely due to the clause concerning “pre-existing medical conditions” So read this clause carefully and get it in writing if the agent says you will be covered if you have heart issues or suffer another SCA while you are away. IN WRITING! Don’t leave yourself vulnerable.

There are numerous common threads that run through so much of the feedback, but the major issue all relates to a lack of a proper follow up protocol for victims and their loved ones by the medical profession, mainly post-discharge. This clearly needs to be addressed and rectified. Please treat SCA survivors with
the respect and dignity they deserve and don’t just ‘shrug your shoulders’ if you don’t know an answer to a question. Tell them you will find out for them and then follow through. And should they request a brain scan, ensure they get one ASAP and have the results explained directly to them and their partner and provide a copy in writing. They are entitled to understand what has happened inside their brain and how that may affect them going forward. You would explain all of this to a breast cancer patient, or someone suffering from Parkinson’s or someone requiring a kidney transplant. So why not to a SCA survivor? Above all, treat them with the dignity and respect they deserve. After all, they survived the almost unsurvivable and are deserving of all you can give them. As Sawyer, et al (2020) states;

“...the current system of care falls short by failing to organize discharge planning and long-term rehabilitation care resources, which, for many patients and their families, may be paramount to improving quality of life after cardiac arrest.”

They suggest the following centralized system of care (see Figure 10.)
I would add a number 7, meet the psychological and social needs of all stakeholders in a holistic manner that meets the needs of all people affected by the event. Such a unified plan involving all stakeholders would more adequately meet the needs of everyone involved. As survival rates of SCA increases due to advances in CPR training and the introduction of AEDs in public areas, there is an increasing need for unified after care provision for the survivor, their family, friends, the community and the EMS and healthcare professionals involved. Suffering a SCA and the resultant cognitive and physical impairment that accompanies most incidents, is difficult enough for the survivor, but the impact on all the stakeholders requires further research and greater attention.
Marketing

As SCA is the leading cause of death in the world with up to as many as 15,000,000 - 17,000,000 deaths per year, we need to heighten awareness of this killer. Few people know what a SCA is and usually confuse it with a heart attack. There needs to be a much more coordinated effort at bringing awareness to this silent, but highly effective killer. Every doctor’s office, waiting area, hospital reception, waiting room, every floor of the hospital, all cardiologists and neurologists, all X-ray and scan rooms, and generally anywhere there is an appropriate opportunity should have at the very least a pamphlet about SCA. Every sufferer and their family should receive as much information as possible before they are sent home to fend for themselves.

There also needs to be a coordinated research plan to forward the latest research information to doctors, nurses, radiologists, and caregivers of SCA survivors and their families. Such a marketing approach would be at least a start in gaining proper awareness of this major killer. Every other major disease that takes significant life has tonnes of medical advice available to patients, family and friends, except for SCA. That’s why I’ve written this book and by freely sharing it online I hope everyone who needs it can get it. At least it would be a start.
Sudden Cardiac Arrest

*A Guide for Survivors, Caregivers, Family and Friends*

Morris W. Shanahan  BA, Dip. Adult Ed, MA

Download this book at: sca-survivors-guide.com You can have it for **free** or a donation in relation to what you think this book is worth to you. Your donation would help pay the upkeep of the website and make a contribution to delivering more AEDs to tourism hotspots around the world in an effort to save more people from suffering or even dying due to SCA.
Ch 21  Research and funding

Most significant health issues have research programmes aimed at reducing the level of incidents as well as determining procedures for after incident treatment. I know of no such programmes for SCA other than the attempts by the Sudden Cardiac Arrest Foundation, a US based non-profit. They have a website but I will leave it to you to determine how effective it is for SCA survivors.

It is about time someone stepped up and set up a not-for-profit fundraising programme to raise money to foster research into SCA:

- Causes,
- Treatment in hospital,
- Follow up treatment of patients,
- Follow up treatment of caregivers, loved ones, friends and health care workers.
Causes

A coordinated approach to the causes of SCA is essential in stemming the number of SCAs happening worldwide. A total of close to 18,000,000 people will suffer from a SCA in the next 12 months. With a worldwide survival rate averaging at best 5-6%, that leaves a total of about 900,000 survivors who will leave hospital and just over 17,000,000 people dead. Of those who survived, 20-40% will die in the first year after discharge from hospital, leaving approximately 585,000 survivors. By the end of five year after hospital discharge, less than 450,000 will still be alive and in various states of wellness to carry on on their own.

This is a major health crisis, yet there is no one, other than the Heart Associations around the world, the Sudden Cardiac Arrest Foundation that is based in the US, and Headway in the UK who focuses on SCA even remotely. Other than a few independent researchers scattered around the world who publish in a variety of places, there are no dedicated Sudden Cardiac Arrest Journals, the occasional Academic Conference happens which incorporates SCA, and some medical journals, such as Circulation, on occasion publish articles on SCA, but nothing
coordinated or funded by any particular organisation. Even the SCA Fondation agrees that:

“...there are currently no nationwide standards for surveillance to monitor the incidence and outcomes of sudden cardiac arrest.”

So the issue doesn’t really get the necessary focus of research attention it deserves.

By providing funding from a not-for-profit organisation and pulling like-minded researchers together in a coordinated effort, the reality of the severity and likely causes of SCA would be enhanced and that would drive even more significant funds into research. While strokes and cardiovascular diseases are decreasing in deaths, SCAs “continue to be a major health crisis.” (Latest Statistics, 2020).

Hospital treatment

There needs to be further research into hospital treatment of SCA patients and some standardisation of processes. I was told by one doctor that implantation of an ICD was standard practice as cardio-thoracic surgeons made significantly more money doing this procedure than looking through all the alternatives for each patient. I certainly hope this isn’t the case, as it would not be a good look for the

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75 Personal Comment. Name withheld by request. 21 March 2020 in New Zealand.
medical profession. In addition, the cooling of the body after an SCA may or may not be best practice for all patients, yet this seemingly is standard procedure. Why? Is there that much evidence to ensure this procedure is the best possible practice for all SCA survivors? I didn’t receive such cooling procedures. Why not? Who is searching for a better alternative? Anyone? I know this is difficult as each SCA patient presents in a slightly different manner, and some are totally unique in how they present, but so much more needs to be done to ensure the best possible in hospital care for survivors and their significant others. At the moment, there appears to be no apparent specific procedures, other than the two mentioned above, to ensure each patient receives exactly what they, as an individual, need. There are some general protocols, but they do not fit all SCAs. Maybe the problem is that each of us is slightly different in our needs and prognosis.

Follow up treatment of SCA patients

This is where the medical profession and medical care providers fall significantly short as there is very little follow up after discharge from hospital. Patients tend to be lumped in with other survivors: stroke, heart attack, Parkinson’s, and others who need follow up for motor skill issues or continued medical care. But for each of these other conditions, there is a structured plan, but
for SCA survivors, there is none. Hospital boards, medical professionals, SCA survivors, caregivers, and even possibly insurance companies, need to work collaboratively together to find procedures that can be adapted for each SCA survivor. But recognition of their needs comes first, which are often more psychological than physical. This is where acknowledgement of a team approach is so important. I have outlined a plan for who and what is required of each participant in the team and I believe implementation of such teams for SCA survivors would significantly enhance five year survival rates and allow patients and significant others to live out healthier, more productive lives.

Follow up treatment of caregivers, loved ones, friends and health care workers

These people suffer just as much as the patient when it comes to a SCA. The impact on each of them is immense, yet nowhere is there a plan to assist them in
recovery. This is unforgivable at best and unethical at worst. The number of loved ones who suffer from PTSD is huge (up to 35%\textsuperscript{76}) and yet there is no assistance for them through the medical services. Partners mention lack of information at discharge, lack of mental health resources and fear it could happen again as major concerns.\textsuperscript{77} This summary of research also suggested there be implementation of support networks and social media groups with expertise from people who are trained in supportive care for others, including significant others—a recommendation that doesn’t seem to have significant follow up at the moment.

Many couples end up divorced as there is no follow up care for the relationship which is immediately under strain due to a SCA. In fact, Fredman, M. \textit{et al} (2014) argued that:

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“The observation that PTSD symptoms in one partner are associated with distress in both partners underscores the need for greater understanding of cognitive, behavioral, and affective processes that interact within and between partners and raises the possibility that enhanced understanding of the dynamic interplay of these factors will lead to opportunities to improve individual and relationship functioning for each member of a couple.”\textsuperscript{78}
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\textsuperscript{76} Sawyer, K.L. et al (March 24, 2020) Sudden Cardiac Arrest Survivorship: A Scientific Statement From the American Heart Association \textit{Circulation} 141:(12)


The children of SCA survivors often struggle emotionally and can exhibit poor behaviour directly after the survivor comes home which can last for years. Their learning suffers and they often have behavioural problems at school or suffer from ADHD. For older children, this can cause rifts within the family and many have ended up walking away from their parent(s) as a result.

Grandchildren are also highly impacted if a grandparent suffers a SCA, yet there is no help for them either. And even parents of both the SCA survivor and their spouse can suffer from PTSD as they never thought their child would die and then be brought back to life. Often there are significant religious issues they have to deal with as well. Yet we do nothing to assist them on this difficult journey. What is required is a coordinated effort by all stakeholders to ensure follow up is covered and these significant others get the help they need.
Summary

It is high time the medical research profession recognised the issues surrounding SCA and put proper procedures in place to help everyone involved from the patient through to the parents to the grandparents to the healthcare professionals who revived the patient to the children and grandchildren and especially to the spouse of the survivor. Having beaten the odds of survival, anyone suffering a SCA deserves our attention as their road to and out of hospital is indeed a difficult journey. Only by treating all participants in that journey to the best possible standards our health care professionals can possibly achieve, can it be truly successful. I believe that is what we want for every patient, young, old or inbetween. So let’s get moving and start the process now to a better future for all concerned in this SCA epidemic.

Ch 22 Conclusion

Be Brave! You are a survivor and have well and truly beaten the odds. Your life and the lives of those around you will never again be the same. Accept that and look forward. There is much you can do to retrieve what you have lost. Neuroscience has shown that the brain has remarkable plasticity and can be
rewired if you know how to do it. Engage a good team around you and never, ever be afraid to ask for help! Remember to be kind—to yourself and those who love you. Try to Pay It Forward as much as you are able, and remake yourself into the person you truly want to be. This is a second chance at life so make the most of it. Be brave and take this opportunity.

To health care providers, doctors, nurses, administrators, cardiologists, neuroscientists, and psychologists and psychiatrists, don’t forget us. You are letting us down by not having a structured plan that meets our needs after discharge from the hospital. We need you onboard to assist us in recovery. Please, I beg of you on behalf of all of us who survive this debilitating event, help us overcome our issues.
by explaining them to us clearly and confidently, by introducing procedures that won’t leave us wanting, by ensuring we get the help we need to get as good as we can get, and by answering all of our questions, or at least finding the answers if you don’t know them. We are ever increasing in number and need your help. Don’t leave us in the wilderness any longer.
Ch 23  Help for SCA survivors

There are numerous places offering assistance to survivors. Listed below are some places you can go to get help and support. Remember, you are by no means alone in this journey so by talking with other survivors, you can better understand what happened, where you are in recovery and, above all, get inspiration knowing you are not alone. Here are the websites:

SUDDEN CARDIAC ARREST MENTOR NETWORK
Register at: https://www.mediconefoundation.org/sudden-cardiac-arrest-survivor/

Sudden Cardiac Arrest Survivors on Facebook (ask to join the group)

Sudden Cardiac Survivors and Friends on Facebook (ask to join)

Sudden Cardiac Arrest Survivors UK Available at:
https://www.suddencardiacaarrestuk.org/

Sudden Cardiac Arrest Foundation
Main page. Available at: https://www.sca-aware.org/sca-network
Network of Survivors. Available at: https://www.sca-aware.org/sca-network
Survivor Stories. Available at: https://www.sca-aware.org/survivor-stories

American Heart Association Available at: https://www.heart.org/

Headway - Improving life after brain injury. Available at:
https://www.headway.org.uk/
Glossary

**AED** – see: Automated External Defibrillator Ablation- Procedure that eliminates extra electrical pathways within the heart that cause fast of irregular heart rhythms.

**ACE Inhibitor**- An ACE Inhibitor (angiotensin-converting enzyme) is a medication that opens up blood vessels, making it easier for the heart to pump blood forward to the body. ACE inhibitors are also used to lower blood pressure.

**Anoxia** - When the brain receives no oxygen at all from the lack of a heartbeat or injury and the blood available is unable to sustain tissue function. Damage to the brain is then called anoxic.

**Arrhythmia** - Also called dysrhythmia. Arrhythmia is a fast, slow, or irregular heartbeat.

**Atrial Fibrillation** - A very fast and irregular beating or quivering of the upper two chambers of the heart. This condition happens just before a cardiac arrest or just as the heart stops all together.

**Automated External Defibrillator (AED)** - a portable electronic device that automatically detects irregular heart rhythms and, if a problem is present, will deliver an electric shock to the heart, allowing it to re-establish a normal rhythm.

**Beta-Blocker, B-B** - Medications given to control the heart rate and rhythm.

**Cardiac Arrest** - A cardiac arrest is when your heart stops functioning and no longer provides blood to the necessary tissues in your body. **Sudden Cardiac Arrest** is the same thing.

**Cardiac Arrest Death** - A sudden Cardiac Arrest resulting in death of the individual.
**Cardiomyopathy** - Disease of the heart muscle, causes decreased functioning of the heart.

**Cardiovascular Disease (CVD)** - Disease affecting the heart and its circulation is referred to as Cardiovascular Disease.

**Cholesterol** - A waxy substance that is produced by the human body. Cholesterol is found in animal fats (beef, chicken, pork), shellfish, and dairy products (butter, milk, cheese, eggs). The body needs cholesterol to produce hormones. When too much cholesterol circulates in the blood, atherosclerosis (hardening of the arteries) occurs and an increased risk of heart attack.

**Coronary Heart Disease (CHD)** - The most common form of heart disease. This type of heart disease is caused by a narrowing of the coronary arteries that feed the heart. The result is not enough oxygen-rich blood reaching the heart.

**CPR** - Cardiopulmonary Resuscitation. A skill that is used by individuals in situations where someone’s heart has stopped.

**Defibrillator** - An electronic device used to deliver an electrical shock to the individual to help the heart establish a normal heartbeat.

**Defibrillation** - A process in which an electronic device gives an electric shock to the heart. This helps reestablish normal contraction rhythms in a heart having dangerous arrhythmia or in cardiac arrest.

**Dysrhythmia** - An abnormal heart rhythm.

**Ejection Fraction (EF)** - A measurement of the amount of blood pumped out of the ventricles. When the left ventricle of the heart contracts, blood is forced into the veins and pushes blood throughout the body. The heart literally releases or ejects the blood out of the left ventricle. Not all the blood is released with each
beat. The percentage that is released or ejected is measured between each heartbeat in a fraction called the ejection fraction. A good ejection fraction is 55% to 60%. At about 30-35% or less you may have cardiac issues and discuss these with your cardiologist.

**Epinephrine** - A vital hormone secreted by the adrenal glands. It plays an important role in cardiovascular and neural regulation. It is produced synthetically for use as a stimulant and in times of emergency can be injected directly into the heart to get it started again.

**Heart Attack** - A heart attack is caused by a circulation or pumping of the heart, one (or more) of the arteries delivering blood to the heart is blocked. Oxygen in the blood cannot reach the heart muscle, and the heart muscle becomes damaged.

**Hypertension** - High blood pressure that is exerted against the walls of blood vessels as blood is pumped through the body.

**Hypertropic Cardiomyopathy** - Is a disease of the myocardium (the muscle of the heart) in which a portion of the myocardium is thickened without any obvious cause. It is most well-known as a leading cause of sudden cardiac death in young athletes.

**Hypoxia** - When the heart is receiving a reduced blood flow but not enough to feed the brain or other tissues properly. Damage to the brain is called hypoxic.

**Implantable Cardioverter Defibrillator (ICD)** - when the heart suffers arrhythmias. This device is a small battery-powered electrical impulse generator that delivers electrical shocks, or pacing therapy, to correct serious ventricular arrhythmias that can lead to sudden death. The defibrillator (ICD) is surgically placed inside the patient's chest. There it monitors the heart's rhythm and identifies serious arrhythmias. Once identified produces an electrical shock, disrupting a deadly arrhythmia.
Ischemia (ischemic = withheld) - reduced nutrient blood flow to organs or tissue resulting in reversible or irreversible damage to tissue.

Lipid - Any fatty substance in the body, including cholesterol and triglycerides.

Long QT Syndrome - An often inherited heart condition in which a delayed action in the heart following a heartbeat forms an irregular heartbeat. These episodes may lead to palpitations, fainting and sudden death due to ventricular fibrillation.

Monounsaturated Fats - Dietary fats, such as olive oil or canola oil. This may lower LDL cholesterol levels. Look for foods high in monounsaturated fats.

Obesity - Being overweight by at least 30% of the ideal body weight.

Pacemaker (Artificial) - An electrical device which delivers electrical impulses to produce a heartbeat of desired frequency (fixed frequency). Modern pacemakers "kick in" on demand only when heart rate falls below a critical (chosen) value and may deliver impulses at rates adapted to physical activity (rate adapted). Implantable pacemakers are the mainstay of treating slow heart rhythms.

Polyunsaturated Fat - A type of fat found in vegetable oils and margarines that does not appear to raise blood cholesterol levels.

Saturated Fat - A fat that is found in foods from animal meats and skin, dairy products, and some vegetables. Saturated fats are usually solid at room temperatures and can increase LDL levels.

Sudden Cardiac Arrest - A sudden abrupt loss of the heart’s electrical system function. The most common cause of the arrest is an irregular heart rhythm (arrhythmia) called ventricular fibrillation (VF), in which the heart ventricles begin to quiver (fibrillate) instead of contract. When this happens, blood is no longer
pumped to the rest of the body, and tissues begin to die after approximately 3-4 minutes.

**Sudden Cardiac Death (SCD)** - Generally SCD is defined as an unexplained (non-traumatic) death that occurs suddenly and unexpectedly within one hour of onset of symptoms. Death is usually due to cardiac arrhythmias ventricular tachycardia/fibrillation.

**Tachycardia** - excessive rapidity in the action of the heart, usually above 100 beats per minute in an adult.

**Trans Fat** - This is a vegetable oil that has been treated with hydrogen in order to make the oil more solid and provide a longer shelf life. It is the "bad" fat which raises LDL (bad) cholesterol.

**Triglyceride** - Fats or lipids from fatty foods that are primarily found in the blood. Main constituent of vegetable oil and animal fats. Excessive triglycerides is linked to the occurrence of coronary artery disease.

**Ventricular Fibrillation (VF)** - A rapid, disorganized, and chaotic contraction of ventricular muscle accompanied by loss of effective pumping of blood. It results in loss of consciousness and death if it is not terminated immediately by delivery of shock with a defibrillator.

**Ventricular Tachycardia (VT)** - A very rapid heart rhythm arising within the ventricles.

**Vertigo** - Dizziness or the feeling that you are falling or watching the world go round.
About the Author

Morris Shanahan obtained his Bachelor of Arts Degree in Psychology from Western Washington University in 1972 and commenced his Masters Degree immediately afterwards. This was interrupted by a draft call up of which he declined. Eighteen months later he was cleared of the draft and left for New Zealand. He did his Masters in Perception and Clinical Psychology at the University of Canterbury in the early 1990s and was undertaking his PhD through LaTrobe University in Melbourne, Australia in the mid-late 2000s. Unfortunately, with his PhD in its final stages, the Christchurch Earthquakes struck on September 4, 2010 and then again on February 22, 2011. Morris lost his business, his home and some close friends. He was later to lose his left lung as a result of all the dust particles he breathed in during the February 22 quake, undergoing two surgeries and over six months of rehab and enforced rest. After he got his health back he started lecturing and giving seminars on the latest neuroscience research highlighting the differences between men and women to better assist people in the workplace (and at home) understand how and why men and women do things differently.

Then, while in New York City in October, 2018, Morris suffered a SCA. Luckily, he was with his son-in-law outside Bellevue Hospital in Manhattan. He was clinically dead for approximately 7–10 minutes and then went into V-fib for close to three minutes. Fortunately, he received CPR within minutes before a femoral line was inserted in his groin by the trauma unit at Bellevue and started
drug therapy to restart his heart. His SCA was not due to cardiovascular disease, but rather to a buildup of fluid in his lung and he was in effect drowning in his own water. He was intubated for approximately 24 hours before coming off the meds and started to breathe on his own. His lung was cleaned out and, within 24 hours, he was sitting up and was finally discharged 5 days later.

He hopes to return to the lecture circuit in the next 12 months as he gains great joy watching people gather an understanding of the gender differences that exist due to neurological variations in brain development and structure.

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Finally a heartfelt “Thank You” to the Trauma Team at Bellevue Hospital who worked their magic on me. Without them, I would not be here today. And lastly to the “little guy who jumped on my chest to give me CPR”\(^7\), I owe you my life. Whoever you are, Thank You Forever!

To ALL the SCA survivors, I say “kia kaha—stay strong”. And good luck to each and every one of you. I hope you found some answers from this book.

Cheers,

Morris William Shanahan
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\(^7\)A quote from Dr. Vincent Major when we discussed who saved me.