



## Practical Parenting Lessons Learned From the Death of a Child

### Especially for Single or College Bound Children over the Age of 18

**W**e have children with the goal of providing for them and guiding them down a path of happiness and success. It is a parent's expectation to have their children outlive them, but sometimes things happen out of order. One can never really be prepared for that, but one could be more prepared.

This is our story. We – Scott and Kate Hogate – unexpectedly lost our son, Kevin, while he was away at college at the age of 20. We share our tragedy, and the difficult lessons we learned, especially if tragedy should strike when you have a child over the age of 18. We hope that no one reading this story experiences a tragedy like our own. But we encourage you to consider taking the simple steps listed below to be able to act clearly and confidently in an emergency with your adult child. We have learned so many others have incomplete checklists and could benefit from our experience. You will encounter many college preparedness guides and checklists, but we have yet to find one that prepares you for an emergency health crisis with your adult child.

Let's start with these important questions:

Do you know how to reach your child's friends, roommates, or significant other? Could you access his or her phone in an emergency? Are you aware of your rights as parents? Are you aware of your son or daughter's rights as a young adult? Are you familiar with the privacy laws that could prevent you from accessing basic information about your young adult? Do you know their feelings about quality of life, organ donations, and their last wishes? Will the people around your child have access to, and know how to use, an automated external defibrillator (AED) in case of an emergency?

As you continue reading, please consider having these tough conversations with your loved ones, especially with those over the age of 18, even if it feels unnecessary or uncomfortable. Dedicating a small amount of time now – while your head is clear – can help you act with clarity and confidence should you ever be in the position to make difficult decisions during a devastating situation.



#### A Rude Awakening

It was the middle of the night, 3:15am on Friday, April 6, when we received a call from an unidentified phone number from Savannah, Georgia. At the time, our son, Kevin, was away attending college in Georgia, and we assumed it was a general announcement from the school related to weather. We received those messages often, so we let the call go.

A second call came a minute later at 3:16am and this time it was a more defined number; instinctively, I knew this was important. My heart pounded when I answered and the voice on the other end asked, "Is this Kevin's mom?" "Yes", I answered. The emergency care doctor proceeded to state, "We have your son in ICU."

My mind raced, struggling to make any sense of that statement. What happened? Was he shot or something? The doctor informed us that Kevin had come into the hospital in full cardiac arrest. His condition was very serious, and we should get to the hospital right away. I was speechless. How was this possible? Kevin didn't have any heart issues, didn't do drugs, drink, or smoke.

We drove nearly 400 miles in the early hours of the morning and finally arrived at the hospital around 8am. Soon after our arrival, Kevin experienced a second cardiac arrest and the staff was able to revive him within fifteen minutes. After things settled down, we learned during the first event that roommates, EMS, and doctors worked on Kevin for some forty minutes and had initially pronounced him dead. Within seconds of the pronouncement, we learned that Kevin came back on his own...a belief of ours that he wasn't ready yet.

During the day, his heart was exhausted, and the hospital staff worked on stabilizing his heart to evaluate his organ functionality. His lungs were a mess. There was also the question of if Kevin did survive all of this, what would his neurological state be? With all the trauma and time Kevin experienced without oxygen and blood flow, there was serious question as to what Kevin's mental state was. The doctors explained that to evaluate Kevin's overall condition including his brain activity, they needed to stabilize him for a 72-hour period.

Around 5:30pm, Kevin experienced a third cardiac arrest. Again, the staff was able to restart his heart, but at this point the doctors were unsure whether he would survive the evening without drastic measures.

It was trying up to the point. The doctors huddled to discuss what options we might have to save Kevin and it was recommended that an Impella device, a heart pump, be inserted to give Kevin the best chance of survival. The surgery was extremely risky, but if we wanted to provide him any opportunity of getting to that 72-hour stabilization mark and surviving, our *only* option was to do the surgery. It was a possibility that Kevin would not even survive the transport to the operating room let alone the surgery itself. Acting quickly, we consented and proceeded with the surgery.

Ultimately, the operation was a huge success and gifted us the opportunity to pass the 72-hour mark and know his neurological state. On Monday morning, April 9, an EEG neurological test was conducted, but sadly, the doctors confirmed what we prayed would not be true, no brain activity. After a long discussion with the doctors and knowing we were comfortable with having met Kevin's wishes for having a quality of life, we made the decision to discontinue life-support. Leveraging our Catholic faith, we arranged for his Last Rites and spent our final hours with Kevin along with his brother, sister, other family and friends. Kevin passed away quickly and peacefully later that Monday evening.

In the end, the doctors' diagnosis was an unexplained complex heart arrhythmia or sudden cardiac arrest (SCA) leading to sudden cardiac death (SCD).

### What is Sudden Cardiac Arrest (SCA) and Sudden Cardiac Death (SCD)?

The answer to this question is just what we wanted to know and what causes it? We had heard about young athletes collapsing and dying while playing sports before but imagine our shock when we heard that our typical, fun-loving, easy-going twenty-year-old Eagle Scout had suffered a major cardiac event with no previous indications of anything. We were left searching for a cause and what we found was eye-opening. What we discovered was that something as simple as stress, cold medication and video gaming could have contributed to Kevin's death. Of course, these by themselves should not have resulted in SCA, but likely these in combination with several other factors triggered Kevin's SCA. And, what exact factors were the main contributors we'll really never know for sure. But, let's get back to the question of what is SCA and SCD, what causes it, and what can you do to help prevent it.

According to the Cleveland Clinic's website ([www.mylevelandclinic.org](http://www.mylevelandclinic.org)):

*"Sudden cardiac arrest (SCA) occurs when the electrical system to the heart malfunctions and suddenly becomes very irregular. The heart beats dangerously fast. The ventricles may flutter or quiver (ventricular fibrillation), and blood is not delivered to the body. In the first few minutes, the greatest concern is that blood flow to the brain will be reduced so drastically that a person will lose consciousness. Death follows unless emergency treatment is begun immediately.*

*Emergency treatment includes cardiopulmonary resuscitation (CPR) and defibrillation. CPR keeps enough oxygen in the lungs and gets it to the brain until the normal heart rhythm is restored with an electric shock to the chest (defibrillation). Portable defibrillators used by emergency personnel, or public access automated external defibrillators (AEDs) may help save a person's life.*

*SCA is **not** a heart attack (myocardial infarction). Heart attacks occur when there is a blockage in one or more of the coronary arteries, preventing the heart from receiving enough oxygen-rich blood. If the oxygen in the blood cannot reach the heart muscle, the heart becomes damaged.*

*Sudden cardiac death (SCD) is a sudden, unexpected death caused by loss of heart function. SCD is the leading cause of natural death*

*in the United States, resulting in about 325,000 adult deaths in the United States each year. Sudden cardiac death is responsible for half of all heart disease deaths. This is roughly equivalent to the combined annual deaths from:*

- Firearms
- Car accidents
- Breast, cervical, colorectal and prostate cancers
- House fires
- Diabetes, Alzheimer's disease, HIV
- Suicides

*SCD occurs most frequently in adults in their mid-30s to mid-40s and affects men twice as often as it does women. This condition is rare in children, affecting only 1 to 2 per 100,000 each year."*

And, to share a list of causes and means of prevention as noted by the Mayo Clinic's website (<https://www.mayoclinic.org/>)

#### "Causes

*Many things can lead to, or cause, an arrhythmia, including:*

- Smoking
- Drinking too much alcohol or caffeine
- Drug abuse
- Stress
- Certain medications and supplements, including over-the-counter cold and allergy drugs and nutritional supplements
- Diabetes
- Sleep apnea
- Genetics

#### Prevention

*To prevent heart arrhythmia, it's important to live a heart-healthy lifestyle to reduce your risk of heart disease. A heart-healthy lifestyle may include:*

- Eating a heart-healthy diet
- Increasing your physical activity
- Avoiding smoking
- Keeping a healthy weight
- Limiting or avoiding caffeine and alcohol
- Reducing stress, as intense stress and anger can cause heart rhythm problems
- Using over-the-counter medications with caution, as some cold and cough medications contain stimulants that may trigger a rapid heartbeat"

#### Sharing Emergency Contact Information

During the first hours after we arrived at the hospital, we wanted to begin piecing together the events that lead to Kevin's condition by speaking with his roommate and friends. However, we quickly realized that we did not have Kevin's roommate's contact information (and later discussed nor did he have ours). Fortunately, the school dean was soon to arrive, and we were able to retrieve Kevin's phone. But again, we were hit with a roadblock. His phone had a numeric code preventing us access. At the same time, we watched texts come in from Kevin's friends inquiring "what's up?", "why aren't you replying?", and "hey buddy, where are you?" But, we were handcuffed without a way to unlock his phone.

With privacy laws and regulations in place, the college was unable to share any updates with us, with Kevin's roommate, and with other



college friends. Nor could the college provide us with their contact information.

As we pondered how we could start contacting his friends, suddenly, we realized that Kevin's phone was part of our family phone plan, and that we could access his activity online. From there, we were able to see incoming and outgoing calls and messages, and find the numbers associated with the activity, but not the contacts' names. With this information, we began to cold call these phone numbers. We introduced ourselves as Kevin's parents and quickly built out his college social circles.

In one of our discussions with the college dean, the dean mentioned that during new student orientation the school recommends roommates saving each other's parents' contact information, or other emergency contact information, on their phones. (While we did do this with Kevin's first year of college, we didn't his second year.) We suggested some additional solutions that could help in the event of an emergency or serious concern. Our suggestions included:

- Develop a family password program using a spreadsheet or phone app ([LastPass on iPhone](#)) to track family member user id's, passwords, etc. (Print and place in sealed envelope after updating quarterly!!!)
- Displaying emergency contact information on paper or a white board in dorms and apartments
- During new student orientation or high school graduation preparation, sharing our experience with parents and students, and strongly encouraging these practices
- Communicating these suggestions annually via school-wide emails, websites, blogs, etc.

### Sharing Phone Access Within the Family

We initially thought that having Kevin's phone and trying to guess at his password would ultimately work. However, as we began the process we saw the display message "1 attempts have failed, 9 attempts remain" and "after 10 attempts, all information will be cleared". We wanted to access his phone not to be nosey, but to obtain any relevant pictures, videos, and a special list in his Notes section that his friends had mentioned would be of interest. This list was a compilation, totaling more than fifty different ideas, of donut flavor combinations. While we knew Kevin loved donuts, we learned from both his lifelong and college friends how much of a donut aficionado he was. This had been his "to do" list saved for when he came home for the summer.

Knowing that Kevin was part of our calling plan, we reached out to our service provider and informed them of the situation, proving that we were the account holder, and proving that Kevin was our dependent. Unfortunately, the provider stated that they could only reset the phone which meant wiping it clean and losing all content. We inquired whether there was a unique "master reset" code for situations like ours that could be used if we were able to verify relationship and ownership. Their reply was a scripted, "No."

We then reached out to the phone manufacturer with the same questions. Unfortunately, their response was also, "No." Growing more disappointed and frustrated, we asked the customer service desk, "Do you think that, if your CEO was in the same position, the Technology Department wouldn't be able to unlock his or her child's phone?" Their reply was, "Nope".

As we discussed this dilemma with others, more examples came to mind:

- What if your child was playing with the device and somehow changed the code. How would you access your phone? Would everything be lost?
- What if that same CEO forgot their password and disabled their phone accidentally?

Is there a "Master Code" for qualifying situations? If not, why not? If the manufacturer, the carrier, and the customer could validate relationship, ownership, and unique serial number to a specific device, then why couldn't a one-time unique master code be provided?

### Adult Children Legal Documents – What are Recommended?

How much power do you have as parents over your young adult child's medical well-being? For most parents, the answer is none. As 18+ year-olds, children are now legally adults. Regulations put into place by The Health Insurance Portability and Accountability Act (HIPAA) were designed to protect patient privacy and, thus, can be a barrier to your immediate needs or desires for information when it comes to your child's health and well-being.

As much as you love and want to care for them, you are not legally able to care for them without their written permission. And, if you have one off to college, you will assuredly learn that lesson at parent orientation. As their college will repeatedly inform you that even though you may be paying the bill, you are not permitted to see their grades, collegiate financial status or personal information such as medical history.

In Kevin's case, he was incapacitated and in grave condition. No one could speak for him but us. One of the first things the hospital asked us was, was if Kevin was married. We verbally confirmed he was not married, but there was not much more to confirm that other than our medical insurance card stating he was our dependent. We answered all the medical staffs' questions and provided whatever information we could to help. And, while we did not seem to run into too many barriers with the hospital in providing them with information, we still felt there was information withheld from us for legal or other reasons.

After Kevin's passing, we reached out to our estate attorney and friend. He had just heard of our news and mentioned that he had created for his own boys (similar in age), a 'College Plan'. This plan consists of four documents including:

- **Will** – Standard document making sure the child's assets will go in accordance with the child's wishes, which would normally be back to the parents.
- **Durable Power of Attorney** – Standard document allowing the parents to sign for the child if the child were to become incapacitated and unable to sign on their own.
- **Advance Healthcare Directive and HIPAA Privacy Waiver** – Key documents allowing parents to make medical decisions and to obtain medical information for their child if the child becomes incapacitated.

We thought this was a great idea and confirmed we would be getting a 'College Plan' for our other children on their 18<sup>th</sup> birthdays. Todd Litman's ([www.toddlitman.com](http://www.toddlitman.com)) College Plan is available for \$300, which includes a \$50 donation to the *Kevin Hogate Graphic Design Memorial Endowed Scholarship* when you mention this story or Kevin Hogate. Money from this scholarship will be used to assist students with interests like to Kevin's at his college. Although these documents are unique to California law, attorneys in other states can prepare similar documents.

### Spouse & Dependent Life Insurance – Is it Worth the Cost?

Preparing for the future, including college costs, can be a long, burdensome, and expensive process. However, as a parent, have you been preparing for your child's funeral? Most likely not. From our recent experience, we were fortunate to have elected spouse and dependent life insurance through just one of our employers. This typically is a few dollars per pay period,



but well worth the minimal cost. For us, the death benefit was \$10,000 and took about six weeks to receive. Funeral services, cemetery plots, and additional transportation (we had to transport Kevin from Georgia to our home state, California) may result in costs more than two or three times a typical death benefit. We recommend enrolling in *both* parent's employer's life insurance options, if available.

#### **Automated External Defibrillators (AED) – A Developing Trend**

It was suggested that if an AED had been in Kevin's dormitory, and used within the first few minutes, his chances of surviving would have been greatly increased. Studies indicate that the use of an AED will improve the chances of survival by 90%, with every additional minute of delay reducing that possibility by 10%. (Wilkoff, 2018)



AEDs are surprisingly affordable, costing approximately a couple thousand dollars. Because of the affordability, numerous institutions, businesses, airports, schools and places of worship now have them in place and are staffed with personnel trained in the use of the devices. Many have had positive results in saving lives. Our goal is to raise awareness so that it is standard practice for all buildings and sports facilities to have them. It would be satisfying to know that all institutions, businesses, airports, schools and places of worship have strategies to obtain AEDs in their current or next year fiscal plans. Do you have any influence in this decision process?

People ask should they be concerned about the possible liability of operating an AED. You should be reassured to know that individuals providing life-saving procedures are legally protected from liability. Good Samaritan laws offer legal protection to people who give reasonable assistance to those who are, or who they believe to be, injured, ill, in peril, or otherwise incapacitated. A Good Samaritan, in legal terms, refers to someone who renders aid in an emergency to an injured person on a voluntary basis. Under the Good Samaritan laws which grant immunity, if the Good Samaritan makes an error while rendering emergency medical care, he or she, in general, cannot be held legally liable for damages in court. Good Samaritan laws are at the State level and exist in most if not all states. There is no Federal law for Good Samaritans.

#### **Preventive Heart Testing for Children and Young Adults**

As children reach their early teens and prepare for high school, many are required to have a physical to participate in high school activities. Physicals are typically very basic in nature and not very expensive. Preventive heart testing among youth is not commonplace with these traditionally offered physicals. However, the cost for testing is very minimal and is sometimes offered by schools as an additional test. Given the cost is very nominal in comparison with the potential risks of experiencing SCA, SCD, or not identifying other potential heart conditions that may ultimately become fatal, why wouldn't you want to be tested yearly as a young adult to potentially avoid such tragedy?



#### **Donor Discussion with Soon-to-be Adults**

Kevin was not a designated organ donor on his driver's license. Do you know what your child's preference is? Have they made a designation? Have you had a discussion with your child about "afterwards"? By happenstance, we were lucky to have recent conversations with Kevin following both of his grandfathers' passings



and understood his desires. He wanted a quality of life or no life. And, he wanted to be intact...as he joked with his mom, "I might still need those (organs)." It was a surreal conversation with his Mom, who is a registered organ donor, knowing Kevin was such a giving person and knowing what his organs could mean to someone else. But, the conversation wasn't carried further with the thought it would be revisited on a later date. And, not only was that conversation left unfinished, we haven't yet had those more in-depth conversations with our other two children either. It's just not a topic that often comes up in everyday conversations. So many others we have spoken with have told us the same thing. We're all in the same boat!

#### **What to Do When Your Child Moves on to College or on Their Own?**

As the end of summer approaches, and your child is preparing to go to college, return to college, or finally move out on their own, what should you do or say? How can you start these important conversations? Share our story, and then consider running through a brief checklist like this:

- Develop a family password program
- Complete "College Plan" documents
- Take a picture of their Durable Power of Attorney, Advanced Healthcare Directive, and HIPAA Privacy Waiver documents and store on a mobile phone or cloud storage (Be sure to save to a file folder as "ICE" (In Case of Emergency))
- Share your child's general and emergency contact info with your child's roommate and the roommate's guardians
- Obtain your child's roommates' general and emergency contact info
- Locate the nearest AED on campus

#### **Lead the Way and Take Charge with Your Young Adult**

Start a conversation now, and don't put it off thinking you don't need to do it today. It's like any insurance, you don't think you need it until you really need it. Take a few simple steps to better prepare yourself and your adult child. It will give you peace of mind and you will be glad you did!

*"The real way to gain happiness is to give it to others"*

*–Baden Powell*



**In Loving Memory of Kevin Riley Hogate**

**1998-2018**