

**Young Sudden  
Cardiac Death:  
A Partner's Grief**



**Cardiac  
Risk in the  
Young**

## Editor

Alison Cox MBE, CRY Founder and Chief Executive

## Sub-Editor

Lily Burke, CRY Bereavement Support Programme Manager

Nat Jenkins, CRY Online and Interactive Media Coordinator

## Produced by

Cardiac Risk in the Young (CRY)

Unit 1140B The Axis Centre, Cleeve Road, Leatherhead, Surrey, KT22 7RD

Web: [www.c-r-y.org.uk](http://www.c-r-y.org.uk) [www.partnersgrief.org.uk](http://www.partnersgrief.org.uk)

Phone: 01737 363222 Fax: 01737 363444 Email: [cry@c-r-y.org.uk](mailto:cry@c-r-y.org.uk)

## *With thanks for their contributions to:*

Michael Burgess OBE

Professor Mary Sheppard MBBCh FRCPATH

*First edition - 2014*

## Grieving

### **Grieving is not something that can fit in to a specific slot.**

Sometimes there can be a great deal of anger about what has happened.

Sometimes trying to cope with the feelings of other family members can exacerbate the grief you are trying to come to terms with.

Sometimes it is difficult to understand and accept that men and women can grieve in very different ways.

Sometimes it is easy to forget that children need special attention. At this time their needs can so easily be overlooked.

Sometimes family members literally wonder if they are going mad with grief and are fearful of sharing such thoughts with others they love.

Sometimes there is a terror of letting family members out of sight and immediate control, in case the same thing happens again.

Sometimes there is the knowledge that the condition that has been diagnosed may be inherited, with all the serious and ongoing implications.

Sometimes you will need to talk things through with a professional counsellor and sometimes you might crave to talk to another person who has suffered in similar circumstances to your own.

### **Each person will feel the need to cope with their loss in a different way.**



*I know first-hand the total devastation, isolation and pain that the sudden loss of your partner brings. Nothing can take away the pain but CRY's unique way of supporting the various aspects of grief can provide great comfort. I feel privileged to be able to give something back to CRY in my role as a Bereavement Supporter and hope that others can draw strength from the stories they will read in this booklet.*

# Contents

Foreword..... 2

Thoughts and Feelings - Extracts from their Stories..... 3

Partners' Stories..... 4

    Max's Story by Jane Davies..... 4

    Tom's Story by Elise Fleetwood..... 6

    James's Story by Shelagh Green..... 8

    Kerry-Anne's Story by Gary Horn.....10

    Joe's Story by Alison Inwood.....12

    Amjad's Story by Fakhra Janjua.....14

    John's Story by Rishka Magowan.....16

    Gemma's Story by Andrew Quew.....18

    Claire's Story by Andrew Reed.....20

    Paul's Story by Carly Sykes-Blowers.....22

The Role of the Coroner Following a Young Sudden Cardiac Death.....24

The Role of the Expert Cardiac Pathologist Following a Young Sudden Cardiac Death..26

The CRY Centre for Cardiac Pathology.....27

About CRY's Bereavement Support Programme.....29

***The 10 authors of these stories:***



---

## Foreword

The young sudden cardiac death of a partner is pulverising. The present, with lifeless options, offers no respite. The future, carefully crafted through a maturing relationship, has been destroyed in an instant. Unlike the memories from birth that exist for a child or sibling, partners can often only reach into their recent past to relive excruciatingly precious moments that must sustain a lifetime of grieving. The pain may soften in time, but will never be extinguished.

The funeral compresses what was and what might have been. A heavy responsibility for one half of the pair - cleaved so brutally apart - to express and share their love with friends and family. Organising the funeral becomes fearfully entangled with recollections of planning their wedding. A final opportunity to emphasise the unique relationship there was. Would always be.

Moving forward into a future built for two seems a betrayal of the love shared. Every step embedded with risk. Endeavouring to again find the independence that had been discarded like a loose unwanted spare skin, becomes part of the overwhelming nightmare each moment represents. Flashbacks haunt dreams and the future lies cold and uninviting; reflecting becomes a passport to despair. The person who relished the security of a deep loving relationship suddenly facing life's hazards with no-one at their side. No more a pair. No longer a future to plan, nor family to dream of. No-one to grow old with. The aching emptiness of a life without them in it.

Losing a partner to young sudden cardiac death rewrites the expectation of life for the one who is left behind. Nothing is safe. Life can turn in an instant, leaving a trail of destruction and desolation. Scrutinising the cherished past, with their back to the solitary future awaiting them. Reluctant to turn and face the prospect of the bleak life ahead and agony of what might have been. Reminded, by their empty bed each night, that they are now alone.



### **Taken from CRY's Bereavement Support leaflet:**

The death of a seemingly healthy child or young adult is so out of order with the sequence of life that its effects are devastating.

It can be hard to believe that this weight will ever be lifted from you. Grief affects not only the emotions - other consequences can include exhaustion, feeling sick and not being able to eat or sleep. These reactions are completely normal at times of intense stress and shock.

It could be important to talk to someone about your feelings, no matter what they are. It is not always easy to do this with people who are suffering from the same loss. Talking to someone outside your immediate family is often the most helpful way forward.

These feelings can go deep inside. If you bottle them up, thinking you have them under control, they will probably resurface later. Expressing such feelings, recognising them and thus including them in your life can help in your life's journey to reconstruct a world that you know will never be the same again.

***Alison Cox MBE, CRY Founder and Chief Executive***

---

---

## Thoughts and Feelings - Extracts from their Stories

I walked into the bedroom and spied a piece of hospital tubing on the floor, left over from the ambulance staff as they had tried to bring Max back to life. I threw myself onto the bed and cried, my chest racked with loud sobs. The pain was so intense it felt as if my heart was breaking in two. A family member or close friend slept nightly on my sofa.

....I was actively involved in preparing him and his coffin. Being such a big part of the goodbye process massively helped me re-gain some order. I gave him a final kiss and was the last person to see him, securing the lid on his coffin. I felt I was looking after him and making sure he was safe. Because of this experience, the next day when the funeral cars turned up at our home, it wasn't such a massive shock to see his closed coffin.

Saying my world turned upside-down doesn't begin to explain it. The external world remained familiar, yet everything was different and out of place. I felt adrift and alone, despite being surrounded by loving, supportive friends and family. Surreal - being there but distant, looking in on it all with a constant, knotted pain in my stomach....

We tried to fathom what may have happened and wondered if she had tripped on the laptop power lead, electrocuting herself; or whether it was carbon monoxide poisoning – desperately searching for answers to the incomprehensible.

I will never be the person I was before and will always have a sadness and pain inside. I didn't just lose Joe that night, but a part of me too. I knew time couldn't move backwards and didn't want time to move forwards. Sad events / stories made me hurt and happy events made me hurt more. How could I be so selfish?

Days and months have gone by and we are starting to adjust to life. Mornings are easier to fill and the kids are at school and doing well; but when night falls and silence is around my thoughts get louder and that is the hardest part of my life. The memories are still fresh as I lie awake and cannot fight the pain in my heart.

John was buried in the suit we had married in less than 2 years before and in planning the readings and music I was struck by how similar and yet how irreparably different things were to planning the wedding....I wrote the longest letter I have ever written to put in his jacket pocket, in his coffin....my final chance to say all the things I wish I'd said before.

I couldn't forgive myself for not being there on the day she needed me most. I have drawn strength from Caitlin, rather than her from me. She was only 2 ½ when this tragedy occurred and one day, noticing I had been crying, asked me if this was because I missed Mummy? When I said 'yes' she replied she missed Mummy too, but not to worry as she would look after me.

I find it comforting to talk about Claire and let out my emotions instead of bottling them up. Claire will always be a huge part of my life and I want to reflect on memories of her every day. Sometimes I find photos incredibly difficult to look at, other days I look and smile; but only now realise how valuable photos are.

Losing someone so loved, so suddenly, so young, gives a unique perspective and teaches you that life is short and precious and not worth wasting on negative emotions. Thomas is the most precious gift that Paul left behind. Sharing our tragedy, talking openly and answering his questions truthfully has helped make him a fantastic son.

*All stories have been approved for publication by those mentioned.*

---

---

## Max's Story by Jane Davies



Max and I met at school. 16 years later we met again and within months were engaged, with our London wedding arranged for 25th September 2010. During dinner with my family the night before, I suddenly felt a panicked urge to be with Max. Answering his mobile he sounded fine. "I love you" he said, and then made a choking noise followed by a long moan. Dad called an ambulance, and 12 minutes later I was racing upstairs to find 3 ambulance staff already giving Max CPR on the floor. His eyes were closed. He seemed not to be breathing. Defibrillator shocks surged through his lifeless body. "Is he dead?" I kept asking. They moved him to Hammersmith Hospital nearby, struggling downstairs with his body, giving CPR before putting him in the waiting ambulance.

We arrived in A&E shortly after and, flanked by my father and brother, a doctor took me into a side room and said that Max had died. Max's mother, Suzanne, arrived - her face horrified as she absorbed the news. I asked my father to check Max again. Surely there was a mistake? But he returned sorrowfully confirming Max was dead. I walked dazed out of A&E, my bones chilled and my body racked with pain, shaking uncontrollably. I asked Suzanne if I could stay with her, wanting to wrap myself close to Max and those that best knew and loved him. I woke from a brief shallow sleep around 5.30am on our wedding day, desperate to see Max and share with him the unbelievable events of the night before. My father drove me to Hammersmith Hospital and we found him on the mortuary table. I rushed over, was surprised at his cold skin, stroked his hair, told him how much I loved and would never forget him. I spoke to Max as if he were alive, unable to face the unimaginable prospect of life without him. On leaving, I reassured him I would be back tomorrow, and the day after.

News spread fast. I observed, detached, as wedding arrangements were cancelled. Guests kept arriving, wanting to stay, afterwards hugging me one by one. The warmth of their feelings enveloped me and our long-planned wedding became Max's wake. I functioned calmly, knowing the worst had not begun, visualising grief as a gigantic tidal wave heading for shore - awaiting its impact knowing when it arrived everything would be decimated. Spending time with Max in the mortuary helped assimilate what had happened on a deep subconscious level. I spoke to him for hours, laughing and crying at memories. Going for the last time before he was moved for the post-mortem I felt I was abandoning my precious fiancé and edged out backwards not wanting to turn my head away. The following weeks were a surreal blur of arranging his cremation, burial, funeral and personal affairs. I was emotional, irascible, wondering how others could continue with their lives when I had an irreplaceable hole in mine. The depth of the pain I experienced was excruciating. My family's support was invaluable. Father reassuring and settling; Mother quietly standing by, ready with a gentle word when it all got too much, which was frequently. My sister went into 'big sister mode', poignantly reminding me of when we were little. My brother building a spare bed for impromptu guests, then replacing it when I commented on its resemblance to a mortuary table. Extended family, brother and sister-in-law, reaching out with loving support. I couldn't articulate then how much this meant, or appreciate that they also loved Max and were hurting too.

Only Suzanne and I were at Mortlake Crematorium on the bleak autumn day we buried Max. We held onto each other, my knees buckling on seeing his coffin and I wept uncontrollably, utterly bereft. People travelled from Europe and the States for his funeral in Brompton Cemetery. I read Sir Philip Sydney's poem 'My true love hath my heart and I have his' and a family friend read Suzanne's moving eulogy. Sam, due to be best man at our wedding, reminded us of the irrepressible sense of fun and uninhibited joyfulness

---

that Max had injected into our lives. My “wedding dress” photograph was placed in the urn with his ashes and afterwards I wanted to hide away forever and never come out. Day-to-day life was reduced to insurmountable obstacles and even getting milk from the corner shop induced panic. I also found that I wanted to ‘reject’ aspects of my life. My circumstances produced so much anguish and misery; I thought if I rejected reminders of my existence, I could somehow escape the pain. I wanted to run away to another country, leave everyone I knew, to escape and create a new identity devoid of loss and grief. Fortunately I had people around me to tell me that escaping my current life was never going to be the solution.

I returned to live in the flat that Max and I shared. I remember walking through the door and seeing the wedding seating plans strewn all over the sitting room. The wedding dress, which had been beautifully designed by a friend, was still hanging wrapped in tissue paper. I walked into the bedroom and spied a piece of hospital tubing on the floor, left over from the ambulance staff as they had tried to bring Max back to life. I threw myself onto the bed and cried, my chest racked with loud sobs. The pain was so intense it felt as if my heart was breaking in two. A family member or close friend slept nightly on my sofa. I woke exhausted and confused by images of death and brutal violence that haunted my dreams, realizing there was no respite as the day held nightmares of its own. My ‘support’ team widened from a trauma specialist to include a psychotherapist, hypnotherapist, acupuncturist and energy healer. This amazing network of people, combined with the unwavering devotion of my family, were crucial to setting me on the path to recovery. Colleagues, my boss and the Managing Director, told me to ‘take off as much time as I needed’ but I didn’t think I could ever return. I thought I had lost not just Max, but my mind as well. A gulf separated me from my friends and I was easily hurt by innocent words, casually delivered, that fell like grenades inside me. Social contact overwhelmed me and flashbacks were easily triggered. I found comfort in our mutual friends - also grieving Max - and sought others similarly affected. However, CRY’s Bereavement Support Day helped alleviate my feelings of isolation and I returned to work 10 weeks after Max died. A colleague met me outside and I recollected how I had left the building an excited bride-to-be. Kind people welcomed me into the team and my job became a life raft of stability; a safe haven I could rebuild my life around. Dr Mary Sheppard at CRY’s Centre for Cardiac Pathology identified Max’s death as SADS and the Inquest recorded ‘Natural Causes’. The coroner reassured me he died painlessly; because I was talking to him on the phone he also died being told he was loved.

Suzanne and I arranged a Retrospective, spanning Max’s life’s work with Sotheby’s Oliver Barker as the auctioneer - which raised an astonishing £27,350 for CRY. I was elated that Max’s friends had come together - 1 year on - to celebrate his life and talent in this way; and I started working with Max’s business partner in their commercial art business ‘3D Joe and Max.’ I am still there part-time. My priorities have changed since Max died. I treasure my family more; am enjoying new artistic pursuits; have learned to trust the instinct which steered me through my darkest hours and am acutely aware that life can be extinguished in an instant. I like to think Max has inspired those closest to him to pursue their goals and make the most of the time they have. He was a vibrant, vital, energetic, funny, kind, caring and unique man who made a big impact on all that knew him.

I can now see his life as a blessing and can only choose to accept his death, not alter it. I no longer hide away; have re-established links with friends and am engaging with the outside world once more. I am ready to move on to the next stage of my life, whatever that may bring.



---

## Tom's Story *by Elise Fleetwood*



I was with Tom when he died on 18th October 2011, 3 days after the 1st Birthday of our beautiful daughter Lacey Belle. He was 28 and I 29. Returning from playing squash, he complained of chest pain, and struggling to breathe collapsed within seconds. The look of horror in his eyes as he left me will haunt me forever. Tom was healthy, fit and full of life. There were no warning signs.

I did all I could. . . everybody did. At the Hospital the medical team allowed me to hold his head and cuddle him as they tried to save him. I wanted to stay forever, my heart breaking as I left. I felt destroyed, melting onto the floor feeling incapable of getting up.

Tom's distraught parents joined me at the Hospital. I crumbled again at our front door in front of a house full of devastated family and friends, feeling sick and disbelieving, as did everyone.

The next 24 hours are a blur. Friends and family came and went, I broke down every time someone new arrived with more memories, and reminders of what I was going to miss in an unthinkable life without him. Those were traumatic early days. Traces of Tom were all around me. I couldn't move anything, leaving his shoes by the front door, his coat on the dining chair. I felt lost and alone, in spite of people all around me. The only person I wanted, needed, who would know how to help me, was Tom. I found it particularly difficult to be with Lacey Belle. Her sweet innocence was heartbreaking. She was the apple of Tom's eye and they adored each other. She had no idea how her life had been forever changed. The cruelty tore me apart every time I looked at her and still does today.

I was permitted to visit Tom at the mortuary, and in the 2 weeks before his funeral spent as much time at the Funeral Directors as I wanted with him, which gave me great comfort. I chose clothes to keep him warm; enjoyed talking to him; holding him; telling him how much he meant to me and thanking him for making me who I am. I shared favourite memories, promising to look after his little princess and giving him photos, letters and drawings from her to keep forever.

When I visited for the final time the night before the funeral I was actively involved in preparing him and his coffin. Being such a big part of the goodbye process massively helped me re-gain some order. I gave him a final kiss and was the last person to see him, securing the lid on his coffin. I felt I was looking after him and making sure he was safe. Because of this experience, the next day when the funeral cars turned up at our home, it wasn't such a massive shock to see his closed coffin. I knew how peaceful he looked and how ready he was to move on. Seeing the huge mass of people waiting outside the crematorium though was overwhelming. I felt self conscious with every pair of eyes on me as I stepped out of the car.

I became fanatical about the funeral and showcasing how special Tom was. I had a photograph collage made; asked close friends and family to nominate songs he loved for a musical tribute; matched the flowers to our wedding floristry; chose a poem, designed the Order of Service, invited friends/family to speak and asked everyone to complete memory cards for Lacey Belle. I cried throughout and if I could have, would have cuddled his coffin for the entire service. I was consoled by everyone's words about him but hated him being cremated. It was what Tom wanted but the process sickened me and I still haven't decided what to do with his ashes. Currently he rests in our bed and I cuddle him to sleep at night. Afterwards I couldn't wait to escape and be on my own. I just wanted to hide and became obsessed with preserving my memories, slept little and lost weight.

---

I was frustrated at how long the post mortem took and that I was given an incorrect timescale for Tom's heart to be returned. It still upsets me that he was cremated without his heart and I wish I had found CRY earlier as they really helped me understand what was happening. The inquest itself lasted several minutes with every statement being read directly from the pathology report that I had already reviewed. It confirmed Sudden Arrhythmic Death syndrome and at first it was difficult accepting there was no reason for Tom's death. However I was reassured that I did not miss any symptoms. Nobody could have predicted this tragedy. 3 months later a bereavement counsellor I had for 6 weeks helped me greatly in coping following Tom's death.

Finding CRY and being matched with a bereavement supporter helped me hugely. Confronting the chasm Tom had left; the empty bed; the home he had created; the paperwork that came with Tom dying; suddenly bring up a 1 year old alone - I felt my CRY buddy was the only person in the world who really understood. She helped me relax about my future fears - dating again, sharing my life with someone other than Tom, and watching somebody else father Lacey Belle. To hear positive experiences from someone that had once been in my shoes was so reassuring and I have thrown myself into fundraising for CRY to re-pay the support they provided when I needed it most. Every event helped distract me from the pain of everyday life.

18 months on, I feel proud of where I am today but life without Tom is very, very lonely. Although I know I am lucky to have such a fantastic network of support around me, nobody is Tom, makes me laugh like Tom did, loves me like Tom did, cares about me like Tom did. It often frightens me that nobody knows of my daily where - abouts. What if something happened to me? How would Lacey Belle cope?

My life has felt very public since he died and I am reconciled to sharing my sadness but miss being private, and having my own life. . . I keep busy with days out and seeing different people but feel I am just an extra in other lives. I miss the relationships I had with some of our close friends and some friendship groups have changed. I have learnt not to be offended. I am changing too. I struggle with jealousy every single day, and watching others lives developing around me wondering: why is Tom not here to enjoy life like his friends are? Why is Lacey Belle not growing up with a daddy? Why has my life been destroyed? Watching couples smiling or comforting each other, seeing little girls laughing with their Daddy's breaks me every time. Hearing engagement/wedding/new baby news used to be so exciting. Now, it just upsets me. I try to always include Tom when talking to Lacey Belle and am desperate for her to understand how fantastic her Daddy was. We kiss his photograph goodnight together.

Tom and I met at Secondary School, started dating at 18, moved in together at 21 and got married in 2009. We were best friends, sharing everything but I accept my life must now carry on without him. Part of me is ready to move forward. I desperately miss loving and being loved in the way only a husband and wife can, hate living as a single-parent, being different, and want to enjoy life again rather than - as recently - spending my days in darkness and pain. But I worry that I will never allow myself to love or trust like I loved and trusted Tom and am scared I won't find anyone good enough to help me parent Lacey Belle. My memories of our life will stay with me always. He gave me so much and made me who I am today.

Tom was a true Gentleman, a proud, honest man who worked hard to provide for his family. He was my everything. I will love him forever.



---

## James's Story by Shelagh Green



On Monday 20th May 2002 James returned from work, kissed me goodbye and left to play cricket. 2 hours later I was told to go to the hospital as he had collapsed. I remember my stomach lurching and understood what it meant when people said their blood ran cold. In A&E a young doctor questioned me, implying James took drugs, and said James was not responding to being “worked on.”

He then confirmed James was dead.

I don't actually know who was in the room – several of the cricket boys and my brother Ian – when, at 34, I learnt I was a widow. James looked so peaceful when I went in to kiss him goodbye and told him “so many people are going to be so sad that you've gone”. We'd known each other 17 years, been together for 14 and married 6 months. Ian phoned our brother Stuart and James's brother Michael, who told their parents. His mum was in poor health, and confronting James's death, not their mum's, added to the family's disbelief.

The days and nights immediately after James died were bizarre. Staying with Ian I recall some moments with great vividness, including his intervention when I phoned James's work the next day trying to explain why he wouldn't be in. I often went on autopilot, recalling little; and woke early, lying in bed with an aching emptiness waiting for sounds of life. I recall sore jaws from clenching my teeth trying not to cry, convinced if I started again I'd never stop. I found the shower was a good place to properly sob. I felt as James's wife it was my job to register the death, although it was hard to hold a pen and sign my name. Everyone gave practical and emotional support but having things to do became important.

There were 8 children in James's family and it was good that some travelled from London in the run up to, and planning of, the funeral. Ian and Mick planned much of it but we all met with the Minister, including Andy, James's best mate and best man. We selected hymns we thought people could sing. Andy read a poem I chose. Mick did the eulogy. Although James was catholic I chose a cremation and celebration of his life rather than a burial, which was what I felt he would have wanted.

I wore black trousers but a colourful top and boots to the funeral; I didn't want to send him off looking like a dowdy old woman. Stuart wisely suggested we visited his coffin alone. It was one of the toughest things I did that day. The funeral was awful but great seeing how loved he had been; feeling supported and cared for; watching Andy reading so emotionally; hearing Mick's moving tribute to his big brother. It provided a kind of punctuation mark in the grieving process, and for me was a rejuvenating experience. I knew returning to living was going to be way harder.

Saying my world turned upside-down doesn't begin to explain it. The external world remained familiar, yet everything was different and out of place. I felt adrift and alone despite being surrounded by loving, supportive friends and family. Surreal - being there but distant, looking in on it all with a constant, knotted pulse in my stomach and a rawness where it felt I had no skin.

My family sidelined their grief, focusing on supporting me. It was particularly hard on Mum who understood the pain of losing a partner because of Dad's death; but now suffered the sudden loss of her much-loved son-in-law, whilst also helplessly witnessing her child's despair. She allowed me to vent my anger, uncritically concealing any hurt she

---

felt, but sometimes I found her anxiety to help frustrating. She couldn't make things better and I felt it was pointless trying.

Moving back to our flat and trying to find some way to connect into life was difficult. Initially it just meant putting one foot in front of the other and reverting to the shower for a sobbing session when necessary. I couldn't sit still, neither wanting to be with people or alone; so I wandered around town near others, but not having to engage with them. On the bus I wondered what was happening in other passengers' lives, knowing they could not guess at mine.

The Procurator Fiscal investigates sudden deaths in Scotland which includes a police visit. The autopsy confirmed no suspicious circumstances so this wasn't traumatic and it helped that one of the officers was my friend Neill. The cause of death was recorded as "Undetermined (pending laboratory investigation)" explaining further tests could take 16 weeks; and was finally updated to Hypertrophic Cardiomyopathy. As testing began on James's family, the sudden death of a cousin and ill health of others had a major impact. Sibling bonds strengthened and dealing with the genetic implications united them even more. Some were reluctant to be screened, which depressed me as his death was easier to accept if others could be protected. Not being screened challenged that.

Mourning James meant mourning my opportunity to have a family and I still wonder what life might have been like with children. James's death made me more independent. At 34 I didn't feel my life was over. I'm who I am now as a result of many experiences and influences over my lifetime – including James - and I have managed to recreate a new life.

However, I'm not sure how I'll feel when, hopefully, such time arrives as I'll have been with my new partner longer than James and I were together. I am comforted that James's family still want to be part of my life and so grateful they've been able to accommodate my new husband, and vice versa. James left home 15 years earlier and a sister remarked it was only seeing me alone that reminded her he was no longer still in Edinburgh. However, it compounded the family's grieving when their mum died 6 months after James.

My family are closer too now, and better value each other. We're more open and demonstrative with a bond and level of trust that feels different. When I really needed them they were there for me and we have a shared experience that has cemented our relationships. The same is true for some key friendships. A core of 4 friends saw me through - making me cry and laugh, giving hope and encouragement. They often didn't know what to do – neither did I – but were just there. They remain amongst the most important people in my life. Some other relationships have drifted which feels fine too. Lives move in different directions.

James was a wonderful bloke and a fantastic husband. Driven, principled, determined - he had a zest for life, loved adventure and was the last to bed if there was a party. His PhD in Tropical Ecology reflected his passion for the environment, with field work in Borneo, projects in Indonesia, and 3 years post-doc research in Cameroon.

He appreciated a Munroe or chaffinch as much as a rainforest or hornbill.

People mattered too and he ensured his family and friends knew that. James was a competitive but fair sportsman. A smart guy, great company, and I'm very lucky that he was part of my life.



---

## **Kerry-Anne's Story** *by Gary Horn*



Kerry-Anne was the girl of my dreams - beautiful, affectionate, caring, thoughtful, exuberant, with a fantastic dry wit. During the 10 years of knowing one another we had lived together for 6 years and spent only 10 nights apart. Our plans and dreams were mapped out and we were looking forward to getting married and having children. We had just celebrated her 30th birthday in July 2008 - a joint affair as mine was the next day.

The evening I returned from football on Wednesday 26th November 2008, Kerry-Anne's shoulder was hurting badly and after an unsettled night she moved into the spare bedroom to allow me to sleep before our routine early rise for work. Shortly after 5am I heard a noise. On checking, I was alarmed to find her lying on her front in the lounge, and thought this was perhaps because of her shoulder pain. However she didn't answer me or move.

I called 999, starting resuscitation whilst constantly talking to her, pleading with her to stay with me and telling her that I loved her. The feeling of relief when the ambulance arrived was replaced with horror at what started happening in front of me and the realisation that it was probably too late. I called the family, urging them to come quickly and distinctly remember hearing their footsteps shortly after, knowing what they were about to confront. We spent some time with Kerry-Anne in utter disbelief, stroking her and then, after being questioned by the police in the bedroom, I had to leave the premises - not being allowed back to the lounge to see her again.

Driving away from the flat my mind and body seemed to shut down. I recall phoning my mum, brother and Kerry-Anne's best friend. On that day and the days that followed, a continuous barrage of visitors came to the family home; and a few days later, I had the extremely upsetting experience of returning to the flat for the first time. I recall seeing debris where the paramedics had been (specifically the protective film from the defibrillator pads) and the ingredients with which she had been cooking dinner the evening before. We tried to fathom what may have happened and wondered if she had tripped on the laptop power lead electrocuting herself, or whether it was carbon monoxide poisoning – desperately searching for answers to the incomprehensible. It was my best friend, Andy, from university (now a cardiologist in Leeds) who mentioned the possibility that the cause was Sudden Arrhythmic Death Syndrome (SADS) which I had never heard of. It was Andy who referred me to Alison and CRY.

Kerry-Anne's funeral was a week later. I arranged this with another family member, working through the various jobs to ensure all went as well as it possibly could for her. Friends and I got together to write her eulogy. I wish I had read at the funeral, but in reality I know I would not have been able to hold it together. We visited Kerry-Anne several times each day in the chapel of rest. The morning of the funeral was cold. I remember wanting to look my best for her; the smell of incense; and the hymns being sung (which now set me off when I hear them). Over 400 people attended the mass and I recall the overwhelming experience of turning to face the congregation to follow Kerry-Anne out of the church. One of the songs at the crematorium - 'You Do Something To Me' by Paul Weller - was to be the first dance at our wedding and I could only leave after being offered a hand by someone to come away.

The next day I woke wondering "what do I do now?" Until then, the funeral and countless visitors had kept us busy. My state of shock had protected me from reality. With Kerry-

---

Anne beside me, I had felt safe and secure and was happy that we could take on whatever challenges life would inevitably throw our way. However, whilst talking to a friend, the thought of life without Kerry-Anne overwhelmed me and I collapsed - ending up in A&E, thinking I was going to die too. This was my first panic attack and was followed by another a few months later. I began to realise that everyone else had moved on, whilst I had not. I started taking my grief out on the tarmac, hitting the road and planning to run the London Marathon for CRY in her memory - my intense endeavours resulting in shin splints which scuppered everything.

Initially, on returning to my flat, I felt scared and easily startled, sleeping on Kerry-Anne's side of the bed with a light and radio on, clutching a pillow for comfort. It was months before I stopped waking at 5am as I had done the morning of Kerry-Anne's death. Suppressing my emotions to be able to operate effectively exhausted me and I sought the doctor's help. Work was difficult. My flat became my refuge and I spent a lot of time there alone, sitting on the balcony looking at the stars and crying to Kerry-Anne "why, why, why?" I became hypersensitive and often, when in public, heard her name being called, or thought I had heard her. Kerry-Anne's ashes were laid in her family grave in Ireland, which felt like a second funeral. The absence of a grave locally led to me placing a memorial bench and tree in Pinner Memorial Park, which we visited on Sundays. I find it very peaceful now, sitting there by the pond.

I was quite apprehensive prior to the inquest, which was 6 months later. I had to provide evidence to help the coroner's court determine the cause of death, which meant publicly revisiting the chain of events. The cause of death was recorded as viral myocarditis which helped my mind to rest. It was the CRY medical day in June 2009 that really helped me understand SADS and rationalise the overwhelming sense of guilt I had been feeling – specifically whether I could or should have done better to keep Kerry-Anne alive. Nevertheless, guilt remained in another form, the fact that I was alive and Kerry-Anne was not – 'survivor guilt'. Attending the CRY annual bereavement support days has also been useful and it is through these support days that I have formed friendships with other families who have also experienced a similar loss, especially important as I have been isolated from relationships which were previously solid. Our common grief brings us close together.

The sudden and unexpected nature of Kerry-Anne's death has made things extremely difficult to come to terms with, providing no time for any preparation or goodbyes. Kerry-Anne was very special and the most precious person in my life – she meant everything to me. She was my soul mate and the person who I confided in and shared everything with, so life has been very empty without her. We were a great team and so coping with the various aspects of daily life has been both a physical and emotional drain. While it is just over 5 years since Kerry-Anne left us, at times it is still hard to believe it is real; but I am hopeful of finding peace and happiness again. Kerry-Anne has made me the person who I am today and so I believe the best way to honour her is to use the love she gave to me in a positive way. In this way, her memory lives on.

My principal outlet to date has been running, as this is something which I am in control of. My marathon training is far more disciplined this time, so I will definitely be running in London Marathon in April 2014 to raise funds for Kerry-Anne's memorial fund with CRY.

Kerry-Anne had a special radiance about her which touched all who were fortunate enough to have met her.

It is so sad that she never got to fulfil all her plans and dreams.



---

## Joe's Story by Alison Inwood



Joe and I had been together since we were 17, went to the same senior school, were both into sport, and got together when we joined the 6th form. In many ways we grew up together. After our trip round Australia in 2008-09 (and not arguing once!) we bought a house and Joe proposed on Christmas Day 2010. The wedding was booked for 5th April 2012.

It was a week before my 26th birthday and a Tuesday night in July. I'd just had a relaxing bath when Joe's mum phoned, a call that was to change my life forever. Joe's dad and brother were at the hospital, as was Joe. On arriving we were shown to a family room. The wait seemed forever before they told us Joe had collapsed whilst running, and died. All words after that are a blur. I was physically there but had shut down. Nothing made sense. Joe's family came and we hugged, consoling each other as best we could but all felt the same...disbelieving and numb with shock! Mum, Dad and 2 of my sisters immediately returned from holiday. My other sister lived close and took me to her home but I insisted on collecting my engagement ring from our house first, to feel as close to Joe as possible. I did not sleep that night, waves of acute pain going through every part of me... longing to get out of the nightmare.

The funeral was 5 weeks after Joe died. It felt like 5 years, with every day a constant battle and just getting up was hard work! I was reading, sometimes all night, trying to find out as much as I could about what could've happened. Nothing was found by Dr Mary Sheppard; Joe had no structural defect of his heart therefore it had to have been caused by an electrical fault. These can only be assessed when the heart is working, therefore we still don't know why Joe's life was taken, which is why it is classed as Sudden Arrhythmic Death Syndrome (SADS).

Joe's family and I discussed the funeral arrangements together. They are such a great family and we all love and miss Joe so much - as do his friends - and wanted the day to go as 'well' as a funeral could do. Instead of choosing wedding songs I was now trying to pick what hymns Joe would want at his funeral. It didn't seem real. I really wanted to do a eulogy but couldn't. Even looking at his coffin made me break down. Joe's mum and younger sister managed to speak at the funeral and I was so proud of them, especially his mum describing Joe as my soul mate. I kept one tissue with me at all times that was doused in Joe's aftershave, helping me feel as close to him as possible. Everyone kept asking how I was. How do you answer that? If truthfully, such as "actually my life has changed without my permission or control, I am disorientated, confused, frightened, sad, angry, unable to get any sort of balance, I am shaken to the core and have no optimism about life anymore" it would've made people uncomfortable; so I kept everything to myself and so people mistakenly thought I was okay. Inside I was a wreck.

I was drained for weeks following the funeral. As reality set in I'd get surges of anger. I tried returning to work 3 weeks later and although everyone was lovely it proved way too early. I eventually went back after 6 months on a gradual return. Every time I drove my car on my own I'd get upset and have to pull over. I wanted to talk about Joe all the time, but didn't like risking getting upset in front of my family. No-one knows what to say. There isn't anything to say. No answers. I have found friends that I wasn't as close to before have been there for me, but have distanced myself from some old ones that weren't. I am so lucky that my sisters are my best friends too.

The inquest was 2 months after the funeral and I had prepared for this, knowing it was

---

---

going to be tough. Joe's mum, dad and I spoke, but it was more of a formality and we learnt little that was new. I didn't want the formalities concluded, realising everyone could then return to their everyday lives; but Joe wasn't here anymore so how could they? My family tried to keep me busy and because I was still living with my parents they found this easier.

I will never be the person I was before and will always have a sadness and pain inside. I didn't just 'lose' Joe that night, but a part of me too. I knew time couldn't move backwards and didn't want time to move forwards. Sad events / stories made me hurt and happy events made me hurt more. How could I be so selfish? My sister's wedding was 5 months after Joe died and was supposed to be 4 months before ours. We had done a lot of our wedding planning together and hoped to have children at the same time. I love my sister so much but this is just one of the many hard things I kept / keep having to face - a constant emotional battle. How could I carry on like this?

About 6 months after, I decided I needed to do something, so Joe's sister, a good friend and I decided to climb Mount Kilimanjaro which gave me a focus. It was heart warming to see so many get involved and helping raise over £24,000 for CRY – an amazing testament to what an incredible person Joe was. We asked for this to go to research to find out what caused this to happen. Although it couldn't help Joe it will in time hopefully help others and provide some answers.

Climbing Kilimanjaro (nearly 6000m / ~20, 000ft above sea level) was the hardest physical thing I've ever had to do (so far), but the most rewarding challenge I've undertaken. It took us 6 days to trek up and down the mountain, battling high altitudes, the elements and lack of sleep. On summit night, when we were struggling walking in the dark with a wind chill meaning lower than zero temperatures, we just thought about Joe and the amazing amount we had raised and had to get to the top! I loved the fact we were that high above sea level and above the clouds for most of the trek. At the summit I felt I was literally at the top of the world and nearest to the sky as physically possible without being in an aeroplane or needing an oxygen mask. It took all the physical, mental and emotional effort I had to do it, but would not change a thing about that trek and it proved to me that I could still enjoy life.

After the trek I started exercising regularly which was really good for me, physically and mentally. I completed some 10k races, a half marathon and am hoping to do a full marathon next. I have found different experiences really helpful and took time off work to travel around the world with 2 close friends. I still break down and get angry, but they know when to give me space. It was refreshing seeing Machu Picchu in Peru, Sugar Loaf Mountain and Christ the Redeemer in Rio; and many more. I always thought how much Joe would love to be there too and revisiting sights that we had been to brought mixed emotions - smiles and sadness together!

Joe and I were together for 8 great years and its comforting to hear his family say I will always be part of them. I'm close with them all, especially his mum. We can talk about Joe literally forever. I'm able to do this more with a smile on my face now, although the tears still sometimes come and when they do it hurts so much it feels as if it's just happened! Joe was more than just my fiancé; he was my best friend too. He was funny, outgoing, caring and the life and soul of every party, with an infectious personality. Everyone wanted to be around him. He is sorely missed but did not waste a second of his life. He loved every minute of it and I enjoyed every minute I spent with him and would still love to hear his funny chuckle which always made me laugh. I love you always JJ xxx



---

## Amjad's Story by Fakhra Janjua



It was Sunday June 10 2012. My fit and healthy young husband of 28 stayed downstairs whilst I put the children to bed. I fell asleep, waking to see his bed empty and finding him motionless on the floor beside the prayer mat in another room. I dialled 999, rang my parents and can remember little more except wanting to wake up from my dream which was not nice. The ambulance team took AJ to the hospital. My little bro (a year younger than me) was there already and sat telling me "everything's going to be OK sis". Then the doctor came and said "we did everything we could, but he is dead".

I looked at my bro and he broke down and sobbed. I was in shock, with many questions coming into my mind. My bro took me to our parents' house where I joined my sleeping children, wondering how to explain that one minute their father is hanging out and having fun with them and then suddenly dead....I waited for them to wake and ask why they were not at home then said, "God has taken your dad away and we will never see him again" still thinking I must soon wake from my horrible dream. The children and I were stunned to find family and friends were waiting when we came downstairs, looking pitifully at us. I wondered how I could wake from my dream, which was fast becoming a nightmare?

My mother gave me some books outlining what to do when you become a widow. These emphasised that there must be a waiting period of 4 months and 10 days called *Idaat* and that God has told us to mourn our husbands by not wearing make up or bright clothing, or socialising during that period. I felt grateful to God for giving us this time, otherwise I do not know how I would have coped.

3 days later we had the funeral and we buried AJ here in the UK. Everyone was coming and giving their condolences. I didn't know how I felt and didn't understand any of it. I just stared at him when his body came and I couldn't cry. I tried, but the tears wouldn't come. I just stood there like a statue. I couldn't say anything. I remember people came over to say things to me but I couldn't understand them. All I saw was their mouths moving and felt their pity. All I kept thinking was I needed to wake from this nightmare.

Family and friends came and brought food to my parents' house, insisting I should eat, but that was the last thing on my mind. They were looking at me, feeling sorry, telling me "it's going to be alright" and that I must be strong for my children as I was now their mother and father. A scary thought....what do I do now he's gone?

After a few weeks I had voices in my head repeating what people had said. Family and friends talked about me in front of me, as if I wasn't there, saying things like "people just don't die". Doubting me, making me feel I was to blame for what had happened. I started to blame myself and cried every night. I felt everyone was pointing fingers at me and doubting me.

My children looked sad and confused. I asked them what they were feeling and what they wanted. My first born, then 6, said "to go back to school". My younger ones, 3 and 5, wanted to go home and sleep in their own beds. My heart melted and broke at the same time. I had been lost in my own little world and neither I nor anyone else had stopped to think about them. I told my mother that we needed to go home and get on with our "so-called" life, but she insisted we stayed another month until Ramadan (fasting) was over.

---

I woke up early the first day of the holy month of Ramadan. My parents had prepared food for keeping the fast and I sat down to eat, bursting into uncontrollable tears, mourning in my heart with my eyes so full I could barely see. Memories of my husband AJ came flooding back - the last year in Ramadan when it was just him and me in our house preparing the food together for our fasts. We laughed often, greatly enjoying each other's company that beautiful month. A perfect team.

This Ramadan was hard and even though my family was there, I felt alone and a burden. The religious festival of Eid followed and my parents insisted we celebrate this with family and friends. When we sat down together, and when the prayer was about to start, I lost control, crying hopelessly. 3 months after the funeral I moved back home. Just me and my kids. Family and friends soon stopped calling, carrying on with life as if nothing had happened. They encouraged me to move on with my life and look forward to the future. I'd think "what future?".

6 months later AJ's post-mortem results arrived. I was alone and started shaking when I opened the letter, going numb with my heart beating very fast. The details in the report were amazing and suddenly I found my strength had returned. The results revealed that AJ had died of natural causes from "Sudden Arrhythmic Death Syndrome (SADS)". Finally I had proof for those that had doubted me. As I no longer needed to prove anything to anyone, I didn't share them, but put the results safely away to show my children when they are older. Reality now hit home, as I fully accepted my husband wasn't coming back. I wasn't in a dream, I was alone and a single parent now.

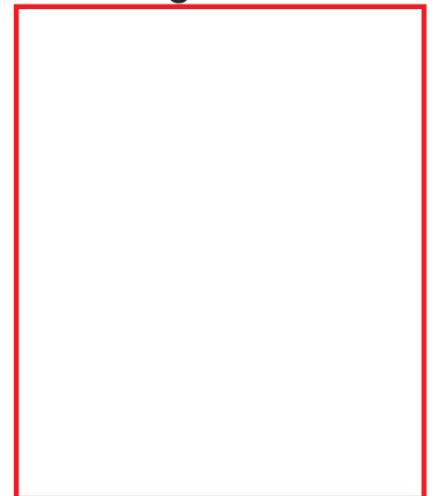
As days went by I discovered new things about life, people and of course my religion - particularly our manual, the glorious Quran. I also recognised there's no harm in asking for help if you need it, but it's best not to depend on anyone. I understood some people had been truly my friends, whilst others were just there for the drama. Many appeared to relish my struggle and seemed disappointed when I began to move on with life – but there were a precious handful of true people who were there for me from the start till this day.

One of them was AJ's mother. We had been married for 9 years and she fell into a state of shock when she heard the news but kept saying "to God we belong and to God we shall return". Her husband, AJ's father, had died in 2005 so this was another sadness for her. But her words comforted us both, keeping us sane. We had visited her to celebrate Ramadan and Eid in July 2011 and although she never got to say goodbye to her son, she gave us permission to bury him in England near his own children so that they could better understand what had happened and know that he was nearby. She was more concerned for his children than herself. Even after all this time she cannot talk to her grandchildren without shedding tears.

Days and months have gone by and we are starting to adjust to life. Mornings are easier to fill and the kids are at school and doing well. But when night falls and silence is around, my thoughts get louder and that is the hardest part of my life. The memories are still fresh as I lie awake and cannot fight the pain in my heart. You'll always live on in my memories AJ. Your eyes found a way to melt my heart.

Why did you have to go? Most of all I remember your smile and trust time to be a healer - it flies by, but you will stay with me forever....

MISS YOU AJ!!



---

## John's Story by Rishka Magowan



We were living in a caravan, awaiting planning permission for our new home, when John suddenly died on his 30th birthday on 31st May 2009. I knew he was dead as soon as I saw him. I quickly realised my CPR wasn't working but felt I couldn't stop. When Dad arrived he continued CPR, then the ambulance came and I knew the words 'shock not recommended' meant there was nothing more to be done. I remember walking out and sitting down outside and a GP informing me my husband was dead.

My step-mum was unhappy we had the ordeal of the police questions, but I just felt numb - desperately wanting them to be gone before my little sister woke up. At the time that seemed to be the most important thing. Although I had been asking to see John throughout the police interview, I felt suddenly terrified when they allowed me in to say goodbye. I was handed his watch and wedding ring and wanted to put them back on him, but was not allowed. When I knelt to kiss him I felt like I was watching myself from above. I phoned Mum and left the rest of the calls to Dad. Then I shut down.

John's mum, dad, brother and sister arrived from Ireland. Devastated. We were unable to arrange the funeral until the coroner had John's cause of death, so spent time visiting places he had loved in Orkney. It was an incredibly difficult time - revisiting all the places that John had been so proud of, but without John there and with a great sadness surrounding us all. John's parents are GPs and arranged for Dr Mary Sheppard to evaluate his heart tissue and for the genetic testing in Amsterdam.

John and I were not religious and had a Humanist wedding, so with his family we planned the ceremony we hoped he would have wanted. It was difficult to know; we hadn't talked about it. His friends came from Belfast staying in tents around our Caravan and the morning of the funeral found us sitting outside on a beautiful bright sunny day, with clear sea views - wanting to enjoy it and shut out the reason for us being there. The arrival of the funeral cars surprised us.

John was buried in the suit we had married in less than 2 years before and in planning the readings and music I was struck by how similar and yet how irreparably different things were to planning the wedding. I was 26 when I got married and 27 when John died. I wrote the longest letter I have ever written to put in his jacket pocket, in his coffin. It was my final chance to say all the things I wish I'd said before. My goodbye. It was when reality began.

The funeral was a bizarre experience. Seeing friends from so many different places, people that had travelled from all over England and Ireland at such short notice; their fear as they looked at me was when what had happened really reached into me. Orkney is full of wild poppies in May which John loved. He knew every type of wild flower and these were represented at the funeral with a beautiful collection from hedgerows and friends' gardens. The Pier Arts Centre allowed us to use their gallery for a whisky toast after the funeral and we had assembled a slide show of John's life to be played. The many people who came to talk to me at the Wake, telling me what an incredibly special person John was, helped so much.

The Orkney funeral was followed by a Memorial Service in County Antrim. I was again struck by how many people had such wonderful stories to tell about John. It was a testament to John's personality that there was lots of laughter, jokes, story-telling and

---

happy memories at his memorial service. It is truly what he would have wanted. I am not saying that it was easy for anyone, there were tears as well, but the easy-going essence of John shone through on these days. I did not cry for a long time after the funeral; just felt numb and disbelieving. I remember seeing everyone I know and love crying, but feeling unable to cry myself. When the crying came afterwards, it went on for a long time.

People often did not know what to say in the weeks after the funeral. Some avoided me if they saw me coming! Reflecting back to my own experience before losing John, I remembered not contacting a friend whose daughter had died because I did not know what to say. Now I would appeal to anyone to please approach the person who is grieving - there is no wrong or right but any words are better than nothing. I had some friends that were there throughout and some that disappeared for a while but have come back. I was lucky to have a huge amount of support and am forever grateful to those that stuck with me through the rough times.

One of the hardest parts of John dying was seeing my younger sisters grieving. They were then 11 and 13 and he had been part of their lives from their earliest memories. Sudden death is hard to explain to an adult, but even harder to explain to young people. John is still in our conversations and I am now able to join in with a smile. One of the main things that helped us in managing our grief is the fundraising we did for John's memorial fund with CRY, which included a monthly sea dip. In the Orkney Islands off the north of Scotland this takes some determination! Many joined us for our final Christmas Eve dip and (yet again) I found it uplifting to see so much fun and laughter, as well as fundraising, come out of our tragedy.

Someone that understood bereavement said to me: at first you cry every hour, then every day, after some time there are occasional days without tears, sometime later you only cry once a week, maybe even once a month – but when you cry you it is with the same despair as the first time. Despite this, you have more and more days without tears, more days when you live your life. I have found this so for me. It is now just over 4 years since John's death, in some ways it feels longer and in some ways so much more recent. I do still miss him every day, but the level of missing is getting easier to manage. Learning how to live again is a difficult process but I feel I am now beginning to live my life again. It is the old cliché and I have heard so many people say “he would want you to be happy” but it is also true. I am beginning to be able to remember John and the happy times, without the searing pain – just with a quieter sense of missing him still.

John had a positive effect on so many people's lives and was loved by so many. He was genuine, kind and brought happiness and laughter everywhere he went. It is through this that he lives on, in the good memories of others. There are a million things in my life that I would never have done without the strength and courage that John's love gave me. This is no less so now, than when he was alive. My experience of loving John and being loved by him has helped me to be able to face losing him.

This poem has greatly helped me in coping with the loss of John:  
*I am there where the river flows and salmon leap to a silver moon,  
where insects hum and the tall grass grows and sunlight warms  
the afternoon.*

*I am there in the busy street, I take your hand in the city square,  
on the market place where the people meet, in your quiet room, I  
am there.*

*I am the love that you cannot see, and all I ask is look for me.*



---

## Gemma's Story by Andrew Quew



Thursday May 26th 2011 started normally, but ended up altering my life. Running late I agreed to collect take away on my way home, then gave my wife Gemma a hug and a kiss and asked if she was OK? She replied she was just tired. I kissed our daughter Caitlin and left for work. That was the last time I saw Gemma alive.

Later, my call went to answer phone, as did her mobile. I assumed she was in the garden or had forgotten her mobile when taking Caitlin to the park as it was her day off. I had no reply 1 hour later so phoned her mother, Pat, asking if she was there. She wasn't. Again I assumed she must be out without her phone. By 4pm I was getting concerned. I left work trying to convince myself everything was fine, collecting take away and getting home at 5.30pm.

Caitlin rushed up excitedly. The front room was strewn with books and toys. I noticed curtains still drawn in the hall, then a pair of feet on the floor of our kitchen and Gemma slumped by the door. My wife, age 30, was dead. Caitlin kept asking if I could get Mummy up off the floor because she couldn't wake her; and it dawned on me that she had been alone most of the day. I asked my boss to deal with the authorities, then sat beside Gemma holding Caitlin, with no concept of time. Pat arrived smiling, asking "well where is she?" and I told her I had just found Gemma dead. Her husband called the emergency services and Gemma's brother, Derek, whilst I contacted her sister, Elaine. Police and paramedics arrived whilst this heartbreaking news sunk in.

We wondered what had happened and I repeatedly replayed the morning over in my head trying to work out what I could have missed. Gemma seemed fine and only a little stressed the night before with her job as a nursery nurse. I work for a funeral director and was comforted by knowing what was going to happen next, but equally knew too much. I visited Gemma both before and after her autopsy. I couldn't take in that she was gone.

Her autopsy was inconclusive and the local pathologist requested her heart to be sent off for more tests. An interim death certificate was issued while it went to inquest. I started to feel like we weren't talking about a person anymore. Gemma had laid her clothes out the morning she died, so we decided to dress her in those. The family were still shell shocked and I made most of the funeral arrangements. I had photos of Gemma enlarged for her funeral and it was surreal to be organising this for my wife of 6 years. In spite of my job, we had never discussed things like this and I found myself making things up as I went along. The inquest said Gemma had died from natural causes (Sudden Arrhythmic Death Syndrome) but we all felt there was nothing natural at all about what had happened. Her family had no history of heart problems and she had shown no signs of any.

As the hearse pulled up outside our house, there was a huge sense of disbelief that this was happening - as if I would suddenly be woken from some terrible nightmare; but the previous 2 weeks of being in an empty bed hammered home the point that Gemma was gone. Myself, her brother, brother-in-law and 3 close friends carried her into the chapel at the Isle of Wight Crematorium. Families choose to do this for many reasons but for me it was my last chance to hold my wife. I was humbled that over 200 people attended her funeral. As I sat with our daughter all I could think of was "why?" and how I desperately wanted just one more moment with her. I spoke, but I can't remember what I said. I felt it would not have been right to speak of how she died, but focused on what a happy-go-lucky girl she was and appealed to everyone to help telling Caitlin in the years to come just how special her Mummy was.

---

I was dazed and off work for 2 months, falling asleep and waking up crying. I couldn't forgive myself for not being there on the day she needed me most. I have drawn strength from Caitlin, rather than her from me. She was only 2 ½ when this tragedy occurred and one day, noticing I had been crying, asked me if this was because I missed Mummy? When I said 'yes' she replied she missed Mummy too, but not to worry as she would look after me.

Losing someone I thought I would spend the rest of my life with has been devastating. It left me with so many unfinished conversations and a lot of guilt, despite the reassurance from the pathologist and doctors that I could not have saved her if I had been there. I feel guilty my child has been deprived of a happy childhood, as she has lost the most important person in her life. When she was unwell and crying for her Mummy I felt useless. It was the one thing I couldn't give her. Caitlin has started recalling things from her past and many of Gemma's best characteristics have been passed on to our daughter. I have made a memory box for collecting her precious things and hung a big picture of them together over her bed, with a smaller one on her bedside for her to kiss goodnight.

Gemma's death hit her parents very hard, especially her mother who was inconsolable and died earlier this year. Gemma's dad cannot talk about her and her brother and his wife and their children took it very hard. The most badly affected seemed to be her sister Elaine, her husband and children, as they were so very close. My mother said she had lost the daughter she never had and Gemma's friends have struggled too. I get angry when people use thoughtless phrases emphasising I must move on. They seem to forget how happy I was with my life before. When mutual friends get married or have children I feel like I am looking through a window into a life I once knew. Our plans and dreams are now just memories of what might have been. Everyone's lives are moving forward yet mine seems a constant circle since Gemma died - and we still don't know exactly what of.

Strangely, I often sensed I was the one consoling others, not the one being consoled. It was often easier to say I was OK, rather than express how I was feeling. In the early days I had some very dark thoughts and considered taking my own life. It was the thought of Caitlin that kept me going. Life is inevitably different for us all now. I would say to anyone reading Gemma's story: don't give up, whether you are in a similar situation to myself with a child, or widowed alone. Even though I wanted the world to stop and take notice, however much you don't want it to, life does go on. Despite the many tears since Gemma died there are just as many smiles. I keep going, not just to honour my wife's memory and for our daughter, but for myself as well.

I've found, like countless others in a similar situation, we are not alone.

Every time I think of my beautiful wife who fell asleep, I recall how she literally fell into my life. Pretty and shy with a gentle strength, no words could ever do Gemma justice. Her smile, laughter and excitement with our first home; finding herself pregnant and our gorgeous daughter's birth. I wish I had told her more often what she meant to me. Although Caitlin keeps me strong, my heart is so empty without her. I wish I could revisit the moments I got wrong and more so the ones I got right. She had the biggest heart of anyone I will ever meet and it's the cruellest thing that it was that which failed. Caitlin will never forget you and how much you loved her.

Simply - I miss you and love you.

Always and forever your heartbroken husband, Andrew x



---

## Claire's Story *by Andrew Reed*



I write this a day after what should have been Claire's 23rd birthday and 5 weeks after the sudden death of my beautiful wife. My strength comes because I still feel she is just away somewhere and will shortly walk through the door. She was healthy, active, fit and cautious. But most of all, the kindest person I know.

We met 5 years ago at work and I finally gathered up the courage to ask her on a first date. I proposed in July 2011 and we got married in October 2012 – the most perfect, happiest day of our lives. One of Claire's classic sayings was "live every day like it's your last, because life is too short". That is how we lived, so in Claire's cruelly short life, she did a lot!

On the 8th March 2013, Claire set off for her friend's hen do, something she had been looking forward to for some time. 16 ladies were staying for a weekend in a mansion just outside Taunton, 2 hours away from where we lived. Claire was perfectly normal that morning - happy, energetic and excited. I kissed her goodbye after we had spent the morning together and never thought in a million years that it was for the last time. We texted each other until 10pm and she was saying what a good time she was having. Then I was woken by one of Claire's distressed friends at 1:30am and will never forget the call and events which followed that haunt me daily, especially every time I try to rest.

I was told Claire wasn't breathing, so called Mum and Dad, asking them to drive me to Taunton ASAP. I was in complete panic mode, looked like a ghost and started being physically sick. One of Claire's friends told me, "Claire was in the Jacuzzi and swimming, we took her outside; she's collapsed and been sick; she's not breathing; we've tried to resuscitate her and now the ambulance are trying to. It doesn't look good".

It was a horrible night - cold, raining, thick fog - and the route to Taunton was all A roads. The worst journey of my life. Clinging on to a tiny bit of hope that Claire was still alive, that the paramedics had resuscitated her, I knew nothing more than what Claire's friends had told me. On the way I called Claire's parents and they immediately left for Taunton too. I spoke to the hospital doctor and the tone of his voice suggested the worst but he refused to say anything until we arrived at the hospital, when I was told Claire was dead. I didn't believe the doctor, asking to see her - and the image of my wife lying lifeless on a bed haunts me to this day. It wasn't my wife lying there, her spirit had gone and there was just a body which the soul had left behind. Mum and Dad were shocked and devastated just like me. No-one believed it – none of it made any sense. Claire's parents arrived soon after and the doctor told them separately that Claire had died. I joined them when they went to see her. The day after Claire's death, I didn't want to do anything but sleep to escape my living nightmare for a short while. I hoped I would wake up and Claire would still be alive.

2 days after her death, I knew the funeral must be arranged. All stuff I didn't want to talk about or do, because I didn't want to believe that Claire had died; but I knew it was my responsibility to give her the best send-off possible by organising a perfect funeral. This kept me going throughout this time, but didn't give me time to grieve. With the help of Claire's family and mine, we arranged a very personal tribute, picking personal songs for the service, which will stay close to my heart forever. Claire's brother, brothers-in-law, cousin and best friends all did readings. At the funeral, from the moment I saw Claire's coffin pull up outside our house, I was in pieces - something I was unprepared for. The crematorium was full with around 500 people, which was a tremendous tribute to how

---

much she was loved.

I felt very down the next day and was still in disbelief. My mind refused to let me process that I just had the funeral for my 22 year old wife. For others, the funeral brought 'closure', but for me this wasn't even the beginning. Since the funeral, there has been a lot of local press interest in Claire's death and in trying to raise awareness of Sudden Arrhythmia Death Syndrome (SADS) and CRY. This kept me busy and gave me something positive to focus on. I feel we have achieved something already - a lot of the local community have booked screenings with CRY and locally many have heard us on the radio or TV.

5 weeks after Claire's death, the inquest still has not been concluded, but thanks to CRY's fast-track pathology unit and Dr Mary Sheppard, Claire's heart results came back promptly. This report made difficult reading – "healthy and normal" are the words that are included in every result of the tests they did. This was very frustrating; she was as healthy on the outside as she was on the inside.

I grieve for Claire every minute of every hour of every day - she loved life, was so young, had so much to live for and we had plenty of plans for a happy life together. It kills me every day to know that her life has just been snatched away from her. For me, life changed instantly. I spent every day with Claire - we met up for lunch, spent every evening together and she was the face I woke up to every morning. We did everything as partners. I think the most time we spent away from each other was our hen and stag do's. She was my everything. Now I wake up to the instant realisation that she's gone and my life has changed forever, which is very difficult to come to terms with. I was so happy and in love with Claire.

I am still living at my parents' house and have been unable to move back into my own home. I cannot ask for a better family than the one I have. They have been there for me since the day Claire died - a shoulder to cry on and someone to speak to. I am incredibly lucky to have such a great family. Without them, I would be in a very dark place right now and I don't know how I would find the strength to carry on, let alone raising awareness of SADS and fundraising for Claire. I chat to Claire's family daily too. I find it comforting to talk about Claire and let out my emotions instead of bottling them up. Claire will always be a huge part of my life and I want to reflect on memories of her every day. Sometimes I find photos incredibly difficult to look at; other days I look and smile, but only now realise how valuable photos are. Thankfully Dad was always snapping so we have no shortage of those.

Such a sad event really shows who your real friends are. Some have been like my family and have been very supportive in this really tough time, which means so much to me. Others see me walking down the street and cross the road or make a conscious effort not to make eye contact.

Claire was the most beautiful, kind, caring and loving person I knew and put every other person before herself, making sure they felt loved. She was intelligent, ambitious and taught us all to live life to the full and not to wait to do things because life is far too short. We all miss you so much Claire, but you will live on forever in our hearts. You are in our thoughts the moment we wake up and you are in the forefront of our minds last thing at night. We will never stop campaigning and fundraising in your memory, that is our promise.

Love your husband, Andy.



---

## Paul's Story by Carly Sykes-Blowers



On Tuesday 12 April 2005 my life changed forever when my 28 year old husband Paul, a semi-professional footballer, collapsed and died during a match.

Our life was so good. We met at work in 1996. He smiled at me, I smiled back. The attraction was instant and we became inseparable. In 2000 we got engaged and bought our own home; married in August 2003 and Thomas was born in July 2004. We were besotted parents and Paul was so proud. He looked after Thomas the day he died. We had 1 hour together when I returned from work, before he started preparing to play his old team, Margate. I stayed home with Thomas when he left, kissing us goodbye, telling us he loved us - and returning minutes later worrying about needing a cap because of his messy hair! I remember laughing as I passed it. Again he kissed me, told me he loved me and was gone...the last time I saw him alive.

His friend Gareth called just after 8pm to say an ambulance was taking Paul to hospital. My parents looked after Thomas whilst Paul's mum and I rushed there. I started feeling sick and couldn't speak. In A&E, Gareth was ashen and shook his head. I was ushered into a family room, where a doctor told me he was extremely sorry but Paul was dead. I didn't believe him. It couldn't be true. He was so fit and healthy. They had tried for nearly 1 hour to resuscitate him and I wanted to be with him to try myself. I remember the physical pain of seeing him lying on the hospital bed, feeling sick, breathless, claustrophobic and wanting to get out of the room but not leave his side - just in case. Eventually I ran out needing to breathe, speak to my parents, best friends, anyone who would listen.

Paul's mum and I are very close and she was inconsolable, but I had no words for her. People continued arriving at the hospital, including his 2 heartbroken brothers. I didn't know what to do with myself. I found myself thanking the football club staff and the ambulance crew who had tried so hard to revive him and was eventually rescued by my Dad, who himself was just so shocked and bewildered. Dad put his arms around me, telling me he wanted to take all of the pain away and was so sorry he couldn't.

Going through my front door was surreal, with Paul's trainers still in the hallway and his coat on the dining room chair. Although late, several people were waiting. I couldn't process that he was never coming home. It took days for the enormity of the situation to sink in; each day with another challenge and another visit from some official. There were so many alien situations to deal with and none more daunting than, age 29, planning his funeral. I desperately wanted to get it right for Paul, but had no idea where to start. The many agonising choices I needed to make - his coffin, the clothes he should wear - will never leave me.

The funeral was in the church where we were married and close to our house with the funeral directors opposite, so we walked all the way with Paul. His mum and I had met the funeral director and been in contact daily. Over 1,000 people came, overflowing outside, listening on a PA system. Police had to stop the traffic and I remember thinking how he would have loved the attention. I was adamant I would read the eulogy and though I found this harder even than writing it, was pleased I did in spite of my tears. The wake was a great celebration of his life - listening to stories about Paul I had never heard; laughing and crying; and marvelling at how many lives he had touched in such a short time. I was especially humbled by the generosity of the Kent football teams who raised thousands of pounds for a trust for Thomas - an amazing legacy, demonstrating the

---

impact of Paul's death and how much he was loved.

Thomas became my reason to get up in the morning, but looking at him constantly reminded me his daddy was dead. How would I manage to bring him up on my own? How and when did I tell him Daddy was dead? Would other children treat him differently? We talked about Paul, looked at his pictures together and I always kissed him goodnight from his dad. People visited, but I hated facing them. Some crossed the road to avoid me. I worried they assumed I was coping, when in reality I was a wreck.

The coroner's officer talked me through the inquest process, explaining Paul had died from 'natural causes'. I mentioned the cold he had before he died, feeling guilty when they implied this may have contributed to his death. I fought for 18 months to get Paul's samples sent to Dr Mary Sheppard at the CRY Pathology Centre and was shocked that the diagnosis of ARVC meant Thomas had a 50% chance of inheriting it. I worry about him daily and he is screened yearly. I cannot contemplate losing Thomas as well.

My fantastic family and best friend kept me going through the following weeks, months and years - taking the knocks when I was angry; cuddling me when I needed comforting; recognising when I needed space; and helping with mundane tasks, especially with and for Thomas, who has a wonderful relationship with them. I stay in touch with Paul's relatives; I have shared so much with his mum and empathised with his brothers' suffering, recognising that everyone's grief is different despite sharing the same pain.

I found it difficult watching others having someone to go home to, planning their future, booking family holidays and days out, having second children; but when such a life-changing event happens you soon find your real friends and learn to not worry about those that drop away. Losing someone so loved, so suddenly, so young, gives a unique perspective and teaches you that life is short and precious and not worth wasting on negative emotions. Thomas is the most precious gift that Paul left behind. Sharing our tragedy, talking openly and answering his questions truthfully has helped make him a wonderful, well-rounded boy and a fantastic son. Through all of this, CRY has been a tremendous support. For me, volunteering as a bereavement supporter has been something really positive to come out of my dreadful situation and is a role I greatly value.

Paul had a zest for life with a smile I can still recollect in an instant. With many friends in all walks of life, he was never short of things to do - whether football, golf, cricket, a night out or a pint in the pub. He was my best friend and soul mate. Generous, funny, fit, athletic, handsome and a brilliant dad. It devastates me that he was robbed of watching our gorgeous son grow up. I feel so lucky to have been his wife, the mother of our son and to have spent such special times together. Paul always thought everyone had a number and when you reached that number your time was up. I'll never believe he thought his number was 28, but he certainly fitted in as much as possible - perhaps just in case?

A tragedy such as this means life can never be the same again, but I have been so lucky to have been found by Ed! He was incredible with Thomas, always acknowledging Paul who is mentioned often by us all. Ed has never shied away from the enormity of what happened to Thomas and I, and has become a part of Paul's family and friends too. I was truly shocked when he wanted to marry me; we married in 2011 with Thomas and my dad giving me away. A year on and Olivia arrived to make our little family complete. Thomas and Olivia have a wonderful dad and I am privileged to have such an exceptional husband. I treasure every precious day....



---

## The Role of the Coroner following a Young Sudden Cardiac Death

Any death that is sudden of unknown cause occurring in England and Wales (Scotland has a different system) will be referred to the local coroner. A coroner is a judicial officer, appointed to a specific territorial district having responsibility for investigating those deaths that are sudden of unknown cause (as well as those that are violent or unnatural or occur in prison). The investigation that he/she initiates may take a number of different forms but is likely to include discussions with and questions asked of the family, the local GP as well as those who were present when the death occurred and any doctor or nurse who may have tried to revive him/her. The investigation process will probably then include a post-mortem examination that will be made by a pathologist. He/she will seek to find a medical reason or explanation for the sudden death. This examination may entail a detailed examination of tissue taken from the body and specimens of blood and urine. The heart may also be carefully examined by a specialist to see if there is any obvious abnormality which may disrupt its proper function.

This whole investigative process may take some time and the coroner will probably decide that the best way forward is for an Inquest to be conducted. This will give the necessary time and opportunity to those carrying through to complete their investigations. An Inquest need not necessarily delay any funeral arrangements.

When the investigations are complete, the coroner will hold the Inquest (a public hearing) when those who can give information about the death will provide evidence. When all the evidence has been received, the Inquest will be concluded by the coroner reaching a decision as to how the death came about (i.e, the medical cause of death as well as the circumstances directly leading to it). This will all be recorded in a document ending with a conclusion or verdict. The coroner will then complete the death registration with the local registrar of deaths.

**The role of the coroner's officer:** The coroner is supported by investigating staff, called coroners' officers. They are either police employees or civilian staff trained to carry through the directions of the coroner. They will generally be responsible for taking the cases forward and be the person that the family should usually contact to ask questions and discuss the progress of a particular investigation. As necessary, they will keep the coroner informed and take their direction from him/her.

**The verdicts and a brief explanation of when/how each might be used in regard to young sudden cardiac death:** At the Inquest, the coroner will reach a verdict in accordance with the evidence before him/her. If the evidence shows that the death arose from a naturally occurring disease process (even though it may have been one that was unknown about during life) the conclusion will probably be that the person died from "**Natural Causes**". If there was an unnatural element, as may be the case of (for example) a person who had a heart attack while swimming, then the verdict may be one of "**Accident**"; which might also be given if the person had been using or experimenting with drink or drugs. An "**Open**" verdict may be given when the evidence does not demonstrate how the death came about and/or the intention of the deceased person is in doubt. A verdict of "**Unascertained**" may be returned if the medical cause of death cannot be found following the postmortem examination.

**Where a narrative verdict fits in:** Sometimes, the coroner may decide that, instead of the suggested "short form" verdicts (e.g. "Natural Causes", etc) he/she will use alternative wording that, on the evidence before him/her, he believes better explains the way in which the death occurred. This is called a "Narrative Verdict."

---

**If the family is unhappy with the service received from the coroner:** In the first instance they should set out their concerns in writing and send it to the coroner for his/her personal attention. In the event that they are concerned with the results of a case then they may have to seek advice as to how to appeal. This may be both complicated and expensive as it may entail an application to the High Court. [See additional note below taken from the latest Coroners Charter.]

**The role of the Chief Coroner:** In September 2012, the Chief Coroner of England and Wales took up his appointment. This is a new appointment created under the Coroners and Justice Act 2009. He has a number of responsibilities including the supervision of training for coroners and their staff, issuing guidelines and directions to provide consistent practice, giving directions in certain cases and generally providing leadership and a figurehead to the Coroners Service in England and Wales. His office is located at: Chief Coroner's Office, Judicial Office for England and Wales, 11th Floor Thomas More Building, Royal Courts of Justice, London WC2A 2LL. Telephone 020 7947 7048.

### **From the Coroners Charter:**

*If you are unhappy with a coroner's personal conduct* you should complain to the Office for Judicial Complaints (OJC). Examples of possible personal misconduct are using insulting, racist or sexist language in court, failing to fulfil judicial duties or inappropriate behaviour outside the court such as a coroner using his or her judicial title for personal advantage or preferential treatment. There is no charge for complaining to the OJC and it can be done online via the OJC website: [www.judicialcomplaints.gov.uk/index.htm](http://www.judicialcomplaints.gov.uk/index.htm) Alternatively, you can download the OJC complaints form and send it to the OJC by fax, post or email. You can also complain by letter or email. The OJC's contact details are: Office for Judicial Complaints, Steel House, 11 Tothill Street, 3rd Floor, 3.01-3.03, London, SW1H 9LJ. Tel: 020 3334 0145. Email: [inbox@ojc.gsi.gov.uk](mailto:inbox@ojc.gsi.gov.uk) Fax: 020 3334 0031. Minicom VII 020 334 0146 (Helpline for the deaf and hard of hearing).

*If you wish to complain about the personal conduct of a deputy coroner or assistant deputy coroner* you should write to the coroner whom the deputy or assistant deputy supports. If you think that the coroner's handling of a complaint about his or her deputy or assistant deputy amounts to personal misconduct of the coroner then you can refer the matter to the OJC. However the OJC cannot deal with the actual complaint against the deputy or assistant deputy coroner.

Further information about complaints about coroners can be found on the OJC website: [www.judicialcomplaints.gov.uk/index.htm](http://www.judicialcomplaints.gov.uk/index.htm)

*If you believe the service you have received falls short of the standards set out in this Charter or wish to complain about the way an investigation was handled or about the conduct of coroners' officers,* you should first write to the coroner. You should copy your letter to the local authority which funds the service. (The coroner's office will be able to advise you of the relevant local authority, if you are unsure of this.)

*If dissatisfied with the council's response the next step is to complain direct to the local authority (the Local Government Ombudsman) at* [www.lgo.org.uk/making-a-complaint](http://www.lgo.org.uk/making-a-complaint), or by calling 0300 061 0614 or 0845 602 1983. Alternatively a complaint may be made in writing to: The Local Government Ombudsman, PO Box 4771, Coventry CV4 0EH.

There is no charge to complain about the standard of service from a coroner's office.

**Michael Burgess OBE**

---

## **The Role of the Expert Cardiac Pathologist Following a Young Sudden Cardiac Death**

Since many of the causes of sudden death lie in the heart it is essential that this is examined by a pathologist with expertise in looking at the heart and diagnosing specific heart diseases.

The expert cardiac pathologist is usually approached by the referring pathologist who has done the initial autopsy with the consent of the coroner.

The referring pathologist will discuss the case with the cardiac pathologist and will then decide whether to send on the whole heart or small samples for the opinion of the cardiac pathologist. The family will be informed of this.

Unfortunately, throughout the United Kingdom there are very few expert cardiac pathologists. Previously, UK based pathologists had nobody to send their hearts to when there was a complex heart case since there is no national referral centre established within the NHS for such investigations.

With the CRY funding donated to St George's Hospital London, we have established a national referral centre so pathologists can have the option of referring cases to the CRY Centre for Cardiac Pathology (CRY CCP) at no cost to the NHS. I have had 16 years experience in this field and have been recognised as an international expert on sudden cardiac death.

At post mortem it is not always possible to identify what the young person has died of by looking at the heart with the naked eye. The expert cardiac pathologist needs histological analysis of small pieces of heart to diagnose many heart conditions. It is always essential to take small pieces of tissues for microscopic analysis at each autopsy. In addition, electrical abnormalities which cause the heart to stop leave no mark in the heart and it is important for the pathologist to make sure the heart is absolutely normal before suggesting that the patient has died of an electrical abnormality.

The process of the pathological investigation usually takes two weeks from referral. With the introduction of the CRY CCP, UK pathologists now have a specialist centre they can send hearts to without worrying about the cost, as the coroner had to fund these cases in the past.

The difference the CRY CCP service has made is that we have designated administrative staff to deal with the complex bureaucracy involved in identification and the use of human material. In addition we have designated scientific staff who can quickly process the heart for microscopic analysis after we have looked at and examined it in detail. The dedicated staff mean we can issue a cause of death within two weeks of receiving the heart from the referring pathologist. In the past these reports were not available to the family for many months, or sometimes years.

Knowing the exact cause of the sudden death comes as a source of comfort and closure for families and helps them to come to terms with the death. It is also essential for cardiological screening of the families if an inherited cause is found.

This will guide the exact type of screening programme the family needs.

***Professor Mary Sheppard MBBCh FRCPath***

## The CRY Centre for Cardiac Pathology

*funded in memory of Howard and Sebastian English*



At least 12 young people die suddenly every week in the UK from undiagnosed cardiac conditions. However, due to a lack of awareness and funding, there can be incorrect or inconclusive recording of the cause of death, and it is believed that there could be many more than the 12 young sudden cardiac deaths every week.

The CRY Centre for Cardiac Pathology (CRY CCP) is funded by CRY and based at St George's Hospital, Tooting. The centre allows coroners to refer cases directly and receive a full report of the actual cause of death, usually within 2 weeks. Previously, some families had to endure a wait of anything from three to 18 months for answers after their tragedy.

The CRY CCP works closely with the CRY Centre for Inherited Cardiovascular Conditions and Sports Cardiology at St George's, to ensure that families are referred quickly for cardiac testing when an inherited/genetic cardiac condition is identified as a possible cause of the sudden death.

Professor Mary Sheppard, one of the world's leading cardiac pathology experts, oversees the running of the CRY CCP. Professor Sheppard established the centre after a grant from CRY in excess of £500,000. The grant was a result of the significant fundraising efforts of a family who lost both a father and teenage son to young sudden cardiac death.



Sebastian English (aged 15 pictured right) died playing rugby 10 years after his father Howard died (aged 32 pictured left with Seb as a baby) - also playing rugby. Because the pathologist gave an incorrect cause of Howard's death, his family were unaware he carried a genetic cardiac condition, highlighting the importance of expert cardiac pathology after a young sudden death.

Howard and Sebastian both died of arrhythmogenic right ventricular cardiomyopathy (ARVC)



---

## Michael Burgess OBE

Admitted a solicitor in 1970, Michael Burgess served as HM Coroner for Surrey and has served as Coroner of The Queen's Household since January 2002. He was Hon. Sec of the Coroners' Society of England & Wales from 1993 to 2003, during which time he was responsible for the day-to-day running of the Society, including close liaison with various government departments. It included periodic meetings with Ministers and regular meetings of dedicated liaison committees. He is now the Society's Legal Secretary. On behalf of all coroners, he prepared detailed submissions and gave both written and oral evidence to Committees of the House of Commons (Road Deaths, Mishaps during Health Procedures and Constitutional Affairs on Coroner Reform); and to Judicial Inquiries (1997-2003). He co-ordinated the Coroners' Society response during the Home Office Review of Death Certification (2000) and the Home Office Fundamental Review of Coroners (2001-2003). He continues to represent the Society in a number of areas including Cardiac Deaths, Drug Deaths, Emergency Planning and Mass Fatalities. He was one of the coordinators of the UK DVI Cadre of Coroners. He has regularly lectured and tutored coroners and outside bodies and interest groups on coroners' practice and procedure. He was one of the joint authors of Halsbury's Laws of England (Coroners Title) and is an Editor of Jervis on Coroners (12th Edition). He has written a Bench Book and Practice Notes for Coroners. He was appointed OBE (June 2009) for services to the administration of justice.



## Alison Cox MBE

Alison Cox MBE is the Chief Executive of the charity Cardiac Risk in the Young (CRY) - the organisation she founded in 1995. In 1993 she instigated the first cardiac screening programme in the UK, working with the Lawn Tennis Association - a programme that was widened to the general public in 1997. As an experienced Counsellor she developed a national bereavement support programme for young sudden cardiac death. In 2002 she started the Surgery Supporters Network (now called *myheart*) for young people who have been diagnosed with a life-threatening heart condition. She has been on the board of various government advisory committees and is a well known and passionate speaker about the impact of young sudden cardiac death. In 2007 she was awarded an MBE for services to healthcare.



## Professor Mary Sheppard, MB. BCH. BAO, BSc. MD. FRCPath

Professor of Cardiovascular Pathology, at St George's Hospital Medical School, University of London, and visiting Professor of Imperial College, London, Mary is a Consultant Histopathologist specialising in cardiothoracic disease. She has a large research and teaching programme working closely with St George's Hospital, the largest in South London. With over 20 years high volume experience Mary organises National and International teaching courses; lectures nationally and internationally and has a research laboratory at St George's Hospital Medical School funded by Cardiac Risk in the Young (CRY CCP) to study young sudden cardiac death. The CRY CCP offers a fast-track pathology service, acting as a national referral centre, with designated specialist technical and administrative personnel dealing with an increasing number of national and international referrals. Mary works closely with the cardiologists at St George's Hospital, as well as collaborating with clinical/scientific teams from other institutions to assist with the screening of relatives of sudden cardiac death victims. Professor Sheppard is President of the Pathology Section of The Royal Society of Medicine; was awarded the coveted Stokes Medal by the Irish Cardiovascular Society for work in 2007; has published widely and co-edited 1 book, co-authored 4 and published the highly respected Practical Cardiovascular Pathology, now in its second print.



## About CRY's Bereavement Support Programme

CRY was founded in 1995 to help families affected by a young sudden cardiac death (YSCD) and young people suddenly diagnosed with a life threatening condition.

Sudden death syndrome is an umbrella term used to describe the many different causes of cardiac arrest in young people (aged 35 and under). These include cardiomyopathies, coronary artery anomalies, ion channelopathies (such as long QT or Brugada syndrome), myocarditis, Marfan syndrome and Wolff-Parkinson-White syndrome (WPW). The exact prevalence for many of these conditions is still not known. Most are due to hereditary disorders, 80% of young sudden cardiac deaths have no prior symptoms.

CRY's Bereavement Support Programme has been developed to help people with their grief following the unaccountable sudden death from one of these conditions of an apparently fit and healthy young child, sibling, relative or friend.

CRY provides emotional support through a network of volunteers who have suffered the sudden death of a child, sibling or partner in this way. These volunteers have achieved British Association of Counselling (BAC) accreditation with Skills and Theory certification, following two years training, so that they can help others come to terms with their tragedies.

Hundreds of people have contacted CRY wondering if there are others who they could talk to, who have suffered similarly. No matter how much professional support is offered (either medical or therapeutic), sometimes just talking to someone 'who has been through such an experience' helps the most.

CRY offers telephone support with our trained bereavement supporters, and also holds bereavement support events.

There are two types of Bereavement Support Days; Regional Bereavement Support Days, and National Bereavement Support Days.

These Bereavement Support Days are for people who would like to understand more about how to cope with the sudden loss of a young person from an undiagnosed heart condition and would like to meet others in the same position.

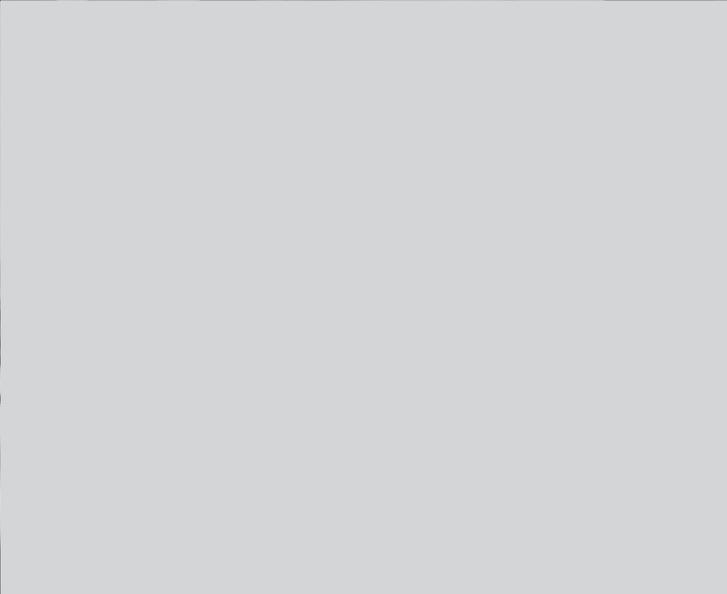
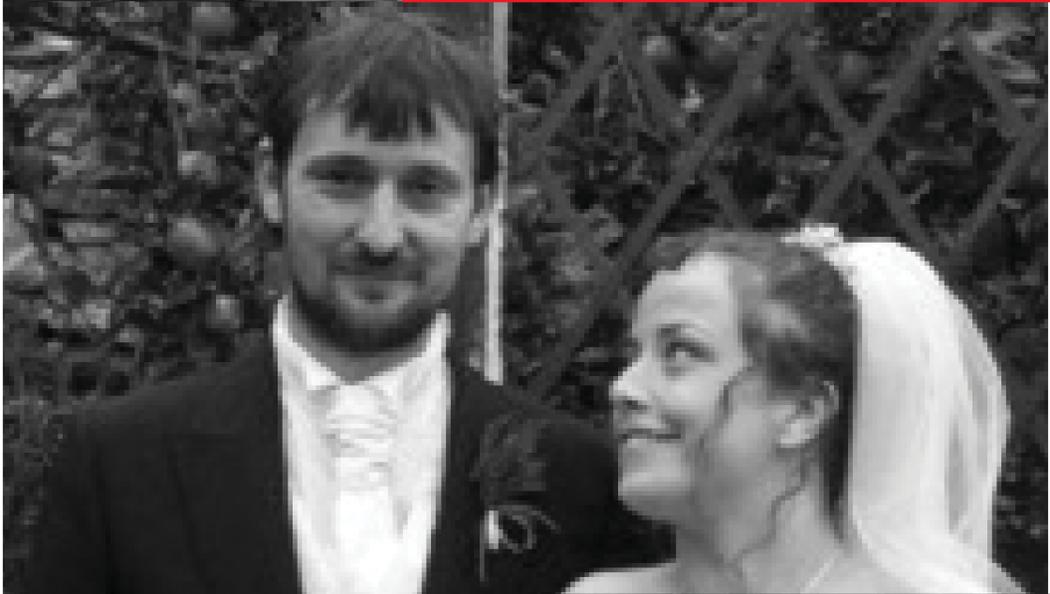
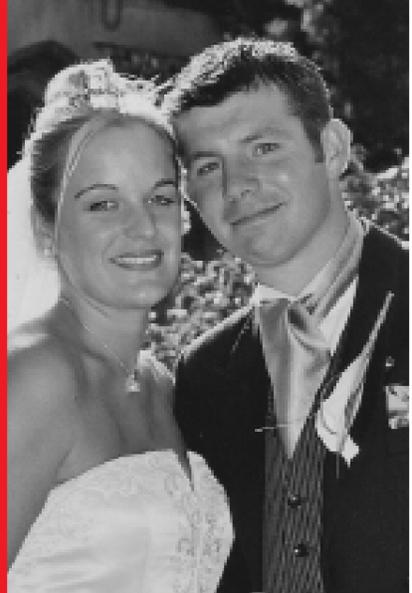
Regional Bereavement Support Days, held in various venues around the UK, are for anyone who has lost a young person (aged 35 and under) to a sudden cardiac death, which people can attend either as a family or on their own.

National Bereavement Support Days are held in central Birmingham. These are exclusive events held specifically for mums, dads, siblings and partners who have lost a young person due to a sudden cardiac death.

Our largest annual event is CRY's Heart of London Bridges Walk. The walk is for bereaved families and supporters to raise awareness and funds for CRY, whilst remembering the young people who have died from sudden death syndrome.

***For more information about the Bereavement Support Days, please call  
CRY's Bereavement Support Programme Manager,  
on 01737 363222, or email [bereavementsupport@c-r-y.org.uk](mailto:bereavementsupport@c-r-y.org.uk)***

**Bereavement Shock Coroner**  
**Pathology Funeral Inquest Love**  
**Information Isolation Sadness**  
**Desolation Numbness Yearning Grief**  
**Anger Distress Mourning Love Support**  
**Kindness Caring Help**  
**Reconstruction ≈ Life ≈ Love**



**Cardiac Risk in the Young**

**Tel: 01737 363222 [www.c-r-y.org.uk](http://www.c-r-y.org.uk)**

