

Remembering

Go ahead and mention my loved one,
The one that died, you know.
Don't worry about hurting me further.
The depth of my pain doesn't show.

Don't worry about making me cry I'm
already crying inside.
Help me to heal by releasing The
tears that I try to hide.

I'm hurt when you just keep silent,
Pretending they didn't exist,
I'd rather you mention my loved one
Knowing that they have been missed.

You asked me how I was doing I
say "pretty good" or "fine"
But healing is something ongoing I
feel it will take a lifetime.

Elizabeth Den-

SUDEP Action is committed to preventing Sudden Unexpected Death in Epilepsy (SUDEP) and other epilepsy related deaths through research, awareness and influencing change. We also work to support the bereaved and to help them channel their grief into preventing future epilepsy-related deaths.

Bereavement support:

support@sudep.org

Getting involved & campaigns:

fundraising@sudep.org

Media:

info@sudep.org

SUDEP Action
12a Mill Street
Wantage
Oxon OX12 9AQ

Call: **01235 772850**
Email: info@sudep.org

SUDEP.ORG



SUDEP Action

Making every epilepsy death count

KEEPING IN TOUCH

January 2016

HELLO THERE ...

Last year, SUDEP Action achieved a huge amount and we look forward to an even better 2016. Our EpSMon App, designed to help people with epilepsy assess their risk, was a finalist at the prestigious Health Service Journal Awards. The SUDEP and Seizure Safety Checklist was the top poster presentation at the 2015 International League Against Epilepsy annual meeting. These prevention tools were highlighted at the American Epilepsy Society meeting in the USA.

We also celebrated 10 years of The SUDEP Global Conversation at the American Epilepsy Society meeting. SUDEP Awareness Day has grown into a global campaign with the support of over 50 epilepsy organisations and patient groups. You can read about all these and more, and about what our fantastic fundraisers have been up to in this latest issue of our newsletter.

Jane Hanna OBE

Chief Executive, SUDEP Action

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SUDEP ACTION HIGHLIGHTS NEW SAFETY TOOLS AT THE AMERICAN EPILEPSY SOCIETY CONFERENCE

We highlighted EpSMon the new Epilepsy Self Monitor App and the SUDEP and Seizure Safety Checklist at the American Epilepsy Society Annual Meeting in Philadelphia. The meeting was attended by around 5000 health professionals from 4 to 8 December. Just think how many people with epilepsy may now be helped to assess their risk!

The Checklist is a tool developed for use by health professionals in clinic to help them and their patients work together to reduce health risks.

EpSMon is a digital version of the Checklist developed for use by people with epilepsy. Dr Rosey Panelli, SUDEP Action's International Research Officer and representative at the AES meeting said: "it was exciting to present these new tools at the AES meeting and to show that our understanding of risk is finally being translated into tools for preventative action which might reduce epilepsy-related deaths."

Jane Hanna, CEO of SUDEP Action said: "The last time we were represented at this large North American meeting was in 1998 and this was to bring news of our international workshop which looked at defining SUDEP and called for urgent action. It is wonderful in 2015 to be back again with our new safety tools. I would like to thank not only Rosey, but Professor Mike Kerr, SUDEP Action

CELEBRATING 10 YEARS OF THE SUDEP GLOBAL CONVERSATION AT THE AMERICAN EPILEPSY SOCIETY MEETING

SUDEP Global Conversation celebrated 10 years of international action at the American Epilepsy Society (AES) Annual Meeting in Philadelphia.



Board member and Vivek Dattani, a SUDEP Action volunteer who both used their time in the US to help."

We also highlighted SUDEP - The Global Conversation and The Epilepsy Deaths Register (EDR) at the AES meeting. The EDR works with international partners to tackle Sudden Unexpected Death in Epilepsy (SUDEP) and other epilepsy-related deaths. The EDR already has around 400 registrations from bereaved families.

The SUDEP Global Conversation is a collaboration between SUDEP Action, Epilepsy Australia and SUDEP Aware, initiated in 2005 by Denise Chapman, Rosey Panelli and

Jane Hanna. The resource, written by experts and bereaved families, has highlighted the work of SUDEP advocates and researchers worldwide.

The collaboration has spread SUDEP awareness globally over the past 10 years through two books in 2005 and 2011 and, since December 2014, as a free online resource only available at www.sudepglobalconversation.com

Dr Rosey Panelli, SUDEP Action's International Research Officer was at the AES SUDEP Action booth to talk to attendees about SUDEP Global Conversation.

Rosey Panelli commented:

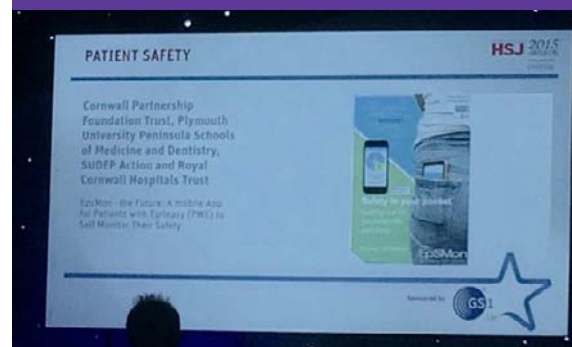
"The difference today in awareness of SUDEP and epilepsy mortality is staggering. Ten years ago we were in Paris and the international community

was just waking up to these issues. From Paris SUDEP - the Global Conversation was taken to Washington, USA and subsequently distributed on North American epilepsy sites. Being at the AES meeting in 2015 helps us continue sharing the conversations with a massive professional audience in the US and all over the world"

Denise Chapman said:

"Ten years on, the SUDEP Global Conversation team continues its commitment to make the scientific research into Sudden Unexpected Death in Epilepsy accessible to all. The progress made in investigating the cause or causes of SUDEP can be traced through the editions of SUDEP – the global conversation, along with the increasing level of community awareness of SUDEP. Until all questions have been answered, we will continue sharing the conversations with our global community."

EPILEPSY SELF-MONITORING APP NAMED FINALIST AT HSJ AWARDS



The Epilepsy-Self Monitoring App was a finalist at the prestigious HSJ Awards in the 'Patient Safety' and 'Using Technology to Improve Efficiency' categories. The App had been shortlisted from around 1600 other entries in the largest celebration of excellence in UK healthcare.

EpSMon was created by a team of partners based at Plymouth University; Cornwall

Foundation NHS Trust; Royal Cornwall Hospital and SUDEP Action. EpSMon is a digital version of the SUDEP and Seizure Safety Checklist, a clinical tool designed to help health professionals monitor and discuss their patients' epilepsy risks and well-being. The Checklist Project was part sponsored by SUDEP Action helped by Kt's Fund, a community fund set up by Liz and Bob Hollingdale in memory of Katie Hallet, a 20-year children's nursing student who died from SUDEP in January 2006.

Launched in July, the App, which has had more than 230 downloads, helps people monitor their own epilepsy by bringing life-saving knowledge to their fingertips. It allows them to assess their risk every three months.

Jane Hanna OBE commented: "To be recognised as a finalist by the HSJ national award panel helps us get our message out. We hope that anyone with epilepsy has a check that they are

seizure free and well. EpSMon is like having a friend who just happens to be an expert on risk in epilepsy. The friend is there whether you need one either because no-one else seems to be able to help or because life is just too busy sometimes to remember about epilepsy. We owe it to Katie and all the other young people who have died to get the message out about EpSMon"

Dr Rohit Shankar, Consultant in Adult Neuropsychiatry at Cornwall Partnership NHS Foundation Trust commented: "I am delighted to see EpSMon named as a finalist in the Health Service Journal Awards just three months after its launch. The idea of the app was originally explored to help people with a learning

difficulty and epilepsy to manage the risks, but with our partners, we have been able to make it available to help everyone with the condition. I am glad the judges have seen the potential of the app to save hundreds of lives across the UK each year."

Dr Craig Newman from Plymouth University Peninsula Schools of Medicine and Dentistry said: "We are pleased that not only is this app making a difference to people's lives, but that it has been recognised for doing so. It is a true team effort."

For more information about EpSMon, visit www.epsmmon.com

WE SUPPORT NHS ENGLAND'S PROPOSAL TO DEVELOP A FIVE YEAR STRATEGY FOR MENTAL HEALTH

While bereavement is seen as a natural part of life, 10% to 20% of people may require further help especially if the death was sudden and unexpected.

SUDEP Action supports the proposal by NHS England to develop a five year strategy for mental health. National bodies will work together until 2021 to help people to have good mental health and access to evidence-based treatment. A survey highlighted that people wished for timelier access to talking therapies.

At SUDEP Action we recognise the benefit of talking, often with those outside the immediate family. We often find it difficult to speak to others due to the differences in grieving and reactions to the death. Or, we may be trying to protect others, by shielding them from the way we are truly thinking and feeling.

We are aware that particularly with epilepsy deaths which can be sudden and at an untimely age, there is a high risk of the bereaved

developing PTSD or traumatic grief. It is therefore essential that people supporting those bereaved suddenly have experience of recognising more complicated symptoms and identify when to refer on to other services.

Some bereaved people may need to be seen by a mental health team and it is important that



there is further specialised help is available. Generally 1 in 4 people in the UK will suffer a mental health problem at some time and bereavement can exacerbate feelings that may have long been hidden.

The Mental Health Task Force Report highlighted three main themes which are prevention, access and quality. The top five areas people prioritised were early intervention; psychological therapies; home treatment; Information to manage mental health and mental health awareness among the public.

At SUDEP Action we recognise these themes and priority areas and already provide support services that fit with this thinking. We will be watching these reports very closely to ensure that our services are the best that we can provide for those who have experienced an epilepsy related death.

SUDEP AND SEIZURE SAFETY CHECKLIST PROJECT WINS TOP PRIZE AT NATIONAL MEDICAL CONFERENCE

The SUDEP & Seizure Safety Checklist project was judged the top poster presentation at the recent International League Against Epilepsy (ILAE) annual scientific meeting in London. Over 200 leading health professionals attended the conference, held from 23 to 25 September; where there was a notable increase in the number of research posters and discussions regarding epilepsy risks, patient safety and SUDEP.

During the three day conference, SUDEP Action staff spoke to numerous health professionals, raising awareness of the charity, its services and its three tools; The Epilepsy Deaths Register, EpSMon and the SUDEP and Seizure Safety Checklist.

Jane Hanna who represented SUDEP Action at the prize ceremony said: "Recognition by the ILAE of the value of the SUDEP and Seizure

At SUDEP Action, we provide:

- A service available to all who have been affected by an epilepsy related death
- A first class service, developed over 20 years, with the bereaved, for the bereaved
- Support immediately after a death and information about the death investigation process
- Answers to questions about what may have happened and why
- Telephone Counselling; allowing people access to therapy from their own homes
- Information about epilepsy deaths and opportunities to meet others similarly bereaved

SUDEP Action also raises awareness of the needs of people with epilepsy and the bereaved.

You can contact the support team via: support@sudep.org or: 01235 772852



Safety Checklist is a great help to our promotion of the checklist to health professionals and our overarching aim of supporting doctors and families with the latest research that can help minimise risk. The development of the checklist is funded by SUDEP Action, through Kt's fund, which was set up by the family and friends of Katie Hallett, a young nurse, who died of SUDEP. We owe it to Katie and other young people who have died to ensure the checklist is used to educate about the importance of appropriate management of seizures and well-being and help save lives"

The Checklist is a tool developed for health professionals to use in clinic to help them and their patients work together to reduce health risks. It uses the latest research into known risks for epilepsy deaths and SUDEP to prompt doctors or nurses to ask a series of questions to the person with epilepsy so that a treatment plan can take account of risk.

SUDEP AWARENESS DAY 2015



Over 120 organisations joined us in spreading awareness on our annual SUDEP Awareness Day on 23 October, 2015. This year we launched a special website which has been accessed from more than 85 countries.

SUDEP Awareness Day is dedicated to raising awareness of SUDEP all around the world. This year, we also rolled out various campaign materials put together with epilepsy organisations from North America, Europe, Australia and our partners on SUDEP – the

Katie's mum Liz Hollingdale, who founded KT's Fund with her husband Bob, commented: *"If EpSMon had been available for Katie to record her seizures and the triggers I truly believe that she would still be with us today. The important information could have been passed to her doctor who could have identified the risks and discussed them further with her using the SUDEP and Seizure Safety Checklist."*

"I urge all Epilepsy sufferers to download EpSMon, and for the medical profession to use the SUDEP and Seizure Safety Checklist. The data recorded can be instrumental in saving future lives."

The ILAE Poster was designed by Sammy Ashby, Policy Officer at SUDEP Action

Health Professionals can register for the checklist at www.sudep.org/checklist

Global Conversation. These included posters and a SUDEP infographic which have been translated into different languages with the help of supporting organisations.

On social media, the campaign was supported by more than 90 epilepsy organisations and groups from all around the world. We also achieved some press coverage right across the UK, much of it thanks to supporters who were willing to share their story to generate media interest.

This year, we went with the theme 'Are You SUDEP Savvy?' to get people talking about SUDEP. The SUDEP Awareness Day campaign encourages people with epilepsy to learn about SUDEP, their individual risk and ways in which they can manage their condition in order to reduce their risk. It also aims to highlight the need for more research into SUDEP to help save lives and honours the lives of all those who have died from the condition.

Charity supporters held various awareness and fundraising events. These included cake sales, school awareness talks and an awareness walk. Some visited their local GPs to hand out SUDEP leaflets and posters while others displayed the campaign posters in their workplace. The SUDEP Action

team held a home-made preserve/cake sale and tombola in Wantage town centre, in Oxfordshire.

We thank you all for helping to make this year's SUDEP Awareness Day a huge success. We are grateful to everyone who organised or went to a SUDEP awareness-raising event, shared their SUDEP story and to all those who donated or helped raise funds.

While we remember those who have died from SUDEP on SUDEP Awareness Day, we also remember the people who have died from other epilepsy-related causes. While SUDEP Awareness Day is intended to help shine a light on SUDEP to help raise awareness of the risk of it, we must not forget the pain of grief felt by all those bereaved.

FAMILY HONOURS RAVIN DATTANI'S MEMORY THROUGH BIG FUN RUN AND TOUGH MUDDER EVENTS

Ravin Dattani's family took part in a fun run to raise funds in memory of their much loved relative. Ravin's aunt, Rajna Dattani: *"It's a great opportunity for the family to get together on a beautiful Sunday morning to take part in the Big Fun Run. We all had a fantastic time walking, jogging and running to the finish line with the added joy of raising money for SUDEP Action in Memory of Ravin Dattani who has been and will always remain a significant part of all our lives."*

As well as the Fun Run, Vivek-Anand Dattani took on the gruelling Tough Mudder in a tribute to Ravin. Vivek commented on the event: *"A gruelling yet fantastic 11.8 miles! Tough Mudder brings together those of all ages, shapes and from different backgrounds with the aim of completing the course, not as fast as you can, but completing the course together! It was an amazing experience facing a number of fears, especially jumping into a skip full of ice and running through a field of*



10,000 volts per live wire dangling down! The great thing is that each and every one of us completed it! I definitely recommend taking a Tough Mudder!"

SINGER'S FAMILY WELCOMES BGT AUDITION FOOTAGE RELEASED IN HIS MEMORY TO RAISE AWARENESS OF SUDEP

The family of Martin Morgan, who died suddenly from epilepsy have welcomed a video of his Britain's Got Talent (BGT) audition. The video received more than 17,000 views in 5 days and has helped raise much awareness of SUDEP.

Martin, an entertainer from Scunthorpe, passed away in July at the age of 37. He had made it through to the final 200 candidates of the talent show but footage of his performance was never aired.

Following his death, Martin's friends and family campaigned through Twitter requesting ITV bosses to release Martin's BGT audition footage to help raise awareness of SUDEP.

Martin's Mum, Helen Morgan, has been raising awareness with SUDEP Action. She says: "I am so, so proud of him, my dear son, why was he taken away so soon at a young age in the prime of his life when he was really enjoying himself so much than he had ever done in his whole life. He had made true friends up in Scunthorpe and I am at a loss as to understand why he was taken from us. We will truly miss and love Martin and will never give up raising awareness of SUDEP, a risk that people need to be aware of."

Martin's sister, Chery Morgan, has also been working with SUDEP Action to spread awareness. She said: "Having seen Martin's audition footage, I was so proud that he fulfilled his dream of performing to the BGT Judges. He was absolutely amazing. We will all remember Martin as the most loveable, caring, supportive person that he was. He has truly left a lasting legacy of music and video with all who had the pleasure of knowing him and judging by the amount of interest in his BGT Audition, Martin

will continue to entertain, growing even stronger after his passing."

"He has left a huge hole in everyone's hearts and will be truly missed. Martin's message to everyone was "Never Give Up, Dreams Can, Do Come True".

In the video, Martin receives a standing ovation after performing Enrique Iglesias's Hero and describes his performance as "a dream come true."

SUDEP Action Chief Executive Jane Hanna, OBE commented: "This video shows what an impact one man can have in life. His family are amazing in using that impact to raise awareness into SUDEP after his death. There are things that people with epilepsy can do to help reduce their risk and we know that Martin's family have already succeeded in reaching out to people with epilepsy to help them stay safe."



Martin Morgan

TONI SLADE SHARES HER STORY IN MEMORY OF HER SON NATHAN

I had boy and girl twins, Nathan and Taryn, whilst living in South Africa at the age of 23. My marriage broke down and the children and I returned to live in the UK in June of 1997, when they were 8 years old.

Nathan had febrile convulsions with fever and at the age of 6, he was diagnosed with epilepsy. First he would go into a 'trance like' state, then these progressed to full tonic clonic seizures whilst he was awake.

Nathan's twin sister, Taryn, is 3 minutes older than him. Taryn was always a leader and Nathan a follower. Nathan was dyslexic and struggled at school. He was bullied at school and struggled to make friends. He struggled with self confidence and trying to understand why his peers were not accepting of him.

Once Nathan started college and work, he came into his own. He made friends and was involved with ten pin bowling. He enjoyed going to the gym. Nathan attended adult education to improve his Maths and English so he could earn more in a better paid job. He bought an expensive camera and equipment and went to college to study photography. He passed his driving test, but twice had to surrender his licence because of seizures; he really wanted to be able to drive again. He bought an expensive bicycle and went riding whenever he could.

Nathan looked up to his sister and wished he could be like her. He saw her moving on in life and felt left behind. She bought her own car and he couldn't have the same. She earned more than him but he couldn't manage a better paid job.

For the past 5 years, Nathan's seizures progressed to nocturnal seizures which



Nathan

remained uncontrolled despite many changes to his medication. He was having a seizure every two weeks; he had felt terrible and looked sallow and fatigued for a long time, whilst trying to lead a fairly normal life.

His death came as an enormous shock to family and friends, and we are still reeling from the events of the last few weeks. I still can't believe I am relating these words to you explaining what has just happened to my beautiful boy; I feel like I am talking about someone else and not my own child. We are left feeling like we are in a bad dream and need to wake up from it now. It doesn't seem real, and his twin sister and I cannot understand or grasp the reality of this.

The post mortem result came back as SUDEP and this is the first we had heard of it. We now want to bring awareness of epilepsy and SUDEP to the fore and raise funds for much needed research because we are all searching for answers as to what happened.

AWARENESS WALK RAISES AWARENESS FOR SUDEP AWARENESS DAY - BY LUCY BIDGOOD



I'm always looking for new ways to raise awareness. With SUDEP Action's second Awareness Day approaching on the 23rd October, I considered ideas. I wanted to create something that would be amenable to everyone, and shout about SUDEP to the wider public. I decided I would arrange an Awareness Walk through London.

I planned it in central London to get the best coverage possible. I contacted Rachel Groves at SUDEP Action who gave me lots of useful information like police contact numbers to get permission.

On Saturday 24th October, we walked from Jubilee Gardens finishing at Speakers Corner in Hyde Park. We carried banners and wore purple.

The atmosphere was amazing; everyone was so upbeat and friendly, considering we were all drawn together through loss. I guess it's because we all felt we were doing something. It was wonderful to meet with others and share our experiences. We had clothing, banners, placards and the SUDEP Action flag giving our message. The Sumaria family in particular had great ideas using 'Placards'; they really stood out in the crowd.

At one point the heavens opened and the rain poured down but it didn't dampen our spirits! We were stopped a lot and asked questions about SUDEP.

A friend, Sandie, came up with the idea of bubbles and another, Caron, to finish by putting petals in the Serpentine to "close the walk down."

Leading the walk, it was amazing looking back and seeing a sea of purple, a lot of people were looking and reading the banners. What made it so great was that we were all on our own personal mission for our loved ones, mine being my husband G. Yet we were united, supporting each other, the greater cause. There really is strength in numbers. The serpentine lake in Hyde Park looked beautiful with hundreds of petals we threw in memory of all those lost to SUDEP.

There were around 80 people. I saw this as a huge success. The walk was around three and a half miles.

I intend to make it an annual event. Next year's SUDEP Awareness Walk is planned for Sunday 23rd October 2016. We hope to inspire those abroad to join us in planning their own walks.

Caron commented: *"It was lovely to meet up with old and new friends. Seeing a wave of purple was reassuring, like a family. It was an honour to carry photos of loved ones for those that could not join us."*

IT IS TIME TO TALK ABOUT SUDEP – BY KATE RASTALL

This story is about our daughter Emily: beautiful, joyful and dearly loved.

Emily was born in 1989, the youngest of two. From a very young age, she was constantly busy with friends, family and her many activities. Occasionally there would be a crisis when she had too many choices, but any spaces she made became vacuums that she quickly filled with new activities. We became used to the constant talking and singing and piles of stuff left lying around as she moved on to the next thing. She knew how to win everyone over and made the most of the benefits of being the youngest.

When she was 15, she was diagnosed with juvenile myoclonic epilepsy. She faced it with her usual positive outlook, coming into the kitchen a couple of weeks after her diagnosis to inform us "I'm glad I have epilepsy. I was always afraid my life was too perfect and something would go wrong. Now it has and it's okay. I can cope." To a friend who got upset, she reassured her, "It's okay. You don't die from epilepsy. That's cancer."

In 2012, aged 22, she celebrated the end of her University exams with a night out with friends and the next morning she was dead. Her body was taken to the local hospital, her computer and phone taken to the police station for safe-keeping and her room sealed as a possible crime scene. We had to wait 3 weeks before we could hold her funeral and a year for the inquest with the verdict of SUDEP. The coroner apologised for the wait.

Here are just some of the things we have learnt from the gift of our daughter's life and our grief following her death:

There is a lot of love in the world.



Kate Rastall with her daughter Emily

Life is precious and to be lived fully, but it's also okay to retreat when you need to.

There are no certainties. Everything can change in an instant.

Grief, vulnerability and brokenness are not signs of weakness but of love and it is our love for our daughter that enables us to carry on without her.

Compassion is neither difficult nor complicated. It's simply being there.

Not enough people know about SUDEP. It is important to share our stories with whoever will listen. It is time to talk about SUDEP.

To read Kate's full story, please visit our SUDEP Awareness Day campaign site: www.sudepawarenessday.org/press

PAT MUSGROVE REMEMBERS HER SON MARTIN ON THE 10 YEAR ANNIVERSARY

My name is Pat. I am a mother to four children and grandma to eight. I work at an elderly person's home and have a dog called Rizzy and a cat called Some Sonil.

I take my dog out for a walk. I go to Bingo two nights a week to meet friends who have been there for me when I needed them most.

Martin was my second son; I have two more children, his sister and brother. Martin was a loving son and brother; he treated his sister like a queen. I want his daughter Lily, who is now 10 years old, to grow up knowing about her dad so that she can be proud of him as I am.

Martin's death changed all our lives. There are bad days and good days, and it seems hard for me to see my other children without missing Martin and to see Lily who looks so much like him. No day goes by without missing Martin and thinking of



Martin

him. On October 4th, Martin's friends are holding a football match for Martin for his 10 year anniversary.

ANDY BROWNE WALKS 120 MILES FOR HIS GRANDSON CHARLIE BURNS



From 31 August to 6 September 2015, my dad Andy Browne, aged 66, walked 120 miles in Cornwall in memory of his grandson Charlie, who loved the county and visited often. We have lots of connections to Cornwall. My husband Baz was born in Redruth, and lived in there until he was 10. My brother currently lives in Falmouth. Furthermore, Marks and Spencer in Hayle have raised money and awareness for us, and most importantly to us, Charlie's stone is in Illogan.

Back at Illogan by the cemetery

Andy Browne's journey started in Illogan, along the South West Path to St Ives and Lands End. He continued through Penzance and Marazion and went as far as Mullion, before heading inland, mainly northwards to Stithians and finally westwards back to Illogan Cemetery. Andy raised £830 for research into the WADD (Wearable Apnoea Detection Device) to help prevent further deaths from epilepsy.



WHAT A DIFFERENCE A DAY MAKES

What a difference a day makes. Yesterday I felt happy to be alive; the sun was out in all its splendor on an October day. Shining bright on the sea at Chesil beach. We walked together hand in hand, our feet almost in unison crunching across the shingle.

Stopped for a coffee outside the cafe and sat on the bench as the sun's rays continued to warm us. We watched the world go slowly by and the mackerel fisherman out in number. Keen to catch those striped blue and silvery wonders. Heavenly, so lucky.

Today it's like someone has turned a switch and the light has gone off in my head. John was out early and the security lamp shone through the window and cast shadows of leaves dancing on the photo frame in the bedroom where I lay. A collage of our family photos.

Grief hit me

A sound like no other escaped with the feeling that my insides were being pulled out through my mouth. I could hardly breathe through the tears. Utterly bereft. Again I asked why? But again no answer came. My young man, my child, my baby captured on camera. Never anymore. Why today do I feel so distraught? I have known for a long time that nothing, nothing can change the cause of my pain. The constant longing and loss.



Matthew

Time's a healer so they say. They're having a laugh, all lies. Time just lays a new fragile skin over the wound but it's so paper thin and opened easily by some sight, some sound, some memory. Fresh once more, bright red and searing.

Memories. Nothing tangible. Just emptiness, a bottomless void.

What a difference a day makes.

Kerina Toates. October 2015. In Memory of my son Matthew.

A NIGHT FOR ELLIS



Friends and family of Ellis Powell organised a ball in her memory. Sophie Hawkins told us about the event: "On the night of the 30th October, Over 300 people gathered together for a night of great music, great food, great people and wonderful fundraising for 'A Night for Ellis'. Held in memory of Ellis Powell, who lost her life to SUDEP at the age of 21, the formal dinner dance was organised to fund crucial research into SUDEP deaths."

"A three course meal was intertwined with performances from friends of Ellis, followed by an information video that shed crucial light on SUDEP. With generous contributions from organisations, prizes for the raffles and the lots in the auction meant that a huge amount of money was raised. We then danced the night away with the help of a live band. It really was a night that we, and Ellis, could be proud of." Special thanks to Sharon Cole for her involvement in the event.

Sharon commented: "The reason I held the ball was to raise awareness and money for research, especially The Epilepsy Deaths Register. We have an idea how Ellis died but none of us understand why, and as parents, siblings, family and friends that is so difficult to come to terms with. Too many loved ones lose their lives to SUDEP and too many families are left destroyed with very few answers and I feel that needs to change."

The night raised around £13,340 for SUDEP Action.



Sharon Cole and Neil

REMEMBERING CAROLYN SANDLAND 10 YEARS ON – 22 OF OCTOBER 2015 BY SANDRA SANDLAND



The day dawned when Carolyn's ashes would finally be buried with her beloved grandma. The church was full as folks gathered from near and far. Some knew Carolyn, many did not, but it was an opportunity to learn about SUDEP.

It was the church where Carolyn went to Sunday school, and where her mum still worships. Carolyn's casket was placed on the mobile Baptismal Font given in Carolyn's memory, placed on pink lace surrounded by white roses and lilies as Carolyn requested following the sudden loss of her Dad and Grandparents. The Communion service remembers our Lord's sacrifice and reminds us of our hope of heaven and God's continuing love and presence in our lives.

The cemetery was bathed in warm sunlight, as Carolyn's casket of ashes and white roses were laid to rest, with her beloved grandma Elsie her best pal, together forever.

Later we watched the new DVD, a work in progress, 'CELEBRATING CAROLYN'S LIFE'. Photos, music and Carolyn singing at

school and with grandma, dancing with her gran, moments with cousins and even on TV with Robbie Williams. All were moved to see our beautiful Carolyn alive and well and were encouraged to read about epilepsy and SUDEP, and to share the information. A memorable occasion.



Jumping for joy

ANNE O'NEIL'S 2015 LONGFORD MARATHON

I was lucky to travel back to Longford, my mum's hometown in Ireland on Friday 28th August to run in the 14th Longford Marathon. I had been involved in a serious car crash about two weeks prior to running the Marathon in aid of SUDEP Action in memory of my little sister Brigid Josephine Marie O'Neill.

Brigid sadly passed away on 27th November, 2001, after suffering a fatal epileptic seizure and drowning in the bath at home. It was a great shock to us all, especially me, as I found my little sister in the bath and she had not had a seizure for four and a half years before that fatal day.

It was a nice dry Sunday morning for the friendly 13.1 mile half Marathon. It's been thirteen years since Brigid passed away. I knew it would be hard because I am still recovering from the injuries from my car crash, but I was determined to finish the race to celebrate my sister's life.

At the start, I thought of Brigid, my best friend. She was a sweet, quiet, hardworking girl and a loving sister who dealt with her epilepsy in her own way by just getting on with her daily life and helping me with my charity work.

I ran across the start line proudly wearing my SUDEP Action T-shirt, with a picture of Brigid and me, and a picture of me wearing my full marathon medal. My T-shirt had a message on the back saying 'Sadly missed but always in my thoughts and in my heart. Love from her sister Anne xxx'.

We had runners from many different countries. The gun went off and the spectators cheered everyone on. The locals provided refreshments along the route. The other runners encouraged me to keep going after reading the back of my T-shirt.



I ran towards the finish with a smile on my face and a sense of pride for what I achieved in my sister's memory.

I felt very proud when I received the medal. I finished in a time of 3:07:48, which I was quite pleased about but also a bit disappointed. Considering the injuries from my car crash, I was lucky to finish.

I am very proud to have raised £2000 so far, to be split between SUDEP Action and another charity.

I would love to think my sister and my mum were looking down on me and helping me on my weary way on a poignant but happy day, having completed my most special and important half marathon.

Epilepsy is a devastating and misunderstood disease that can affect families in the most tragic way. It is a heart-breaking experience to deal with an unexpected death of a loved one.

CHARLIE'S SUNFLOWER BALL



In April 2015, we were inspired to hold a Charity Ball in memory of our gorgeous little boy Charlie, after attending a Ball held by Emma and Des Carter, in memory of their gorgeous daughter Rosie.

We called our event 'The Sunflower Ball' because when Charlie died, we struggled with what type of flower to put on his coffin. What flower do you put on the coffin of a child? We chose Sunflowers, as they were colourful and bright: reminding us of everything about Charlie, his smile, his happy personality, that he loved the summer and being outside.

October is the toughest month of the year for us. Charlie died a week after his 10th birthday, and was also cremated the same month, so needing a distraction from the sad times, we chose the 3rd October 2015, the day before Charlie's 14th Birthday.

We have been supported by so many people since Charlie's death, and received so many offers of help, now was the time to call upon all of those offers. Once The Stone's Hotel in Salisbury kindly agreed to donate their venue and facilities for the event, we used our most powerful tool, our story. The support we received from local media and businesses was extremely humbling.

Over 150 guests from far and wide, and several families we have become firm friends with through our sad link with SUDEP, joined us for the night that was such a fitting tribute to Charlie. There was champagne, a three course meal, The Salisbury Plain Military Wives Choir, The Rock Choir, and Luke Price, a Tenor from the Royal Opera House in London. After his rendition of 'Bring Him Home' from Les Miserable, there wasn't a dry eye in the house!



We showed slides of Charlie and some of the fundraising we have done since his death. This was followed by a video speech from Clare Perry MP.

This led into the Auction, compared by Faye Marsh and Martin Starke from SPIRE FM. A local live band 'The Rookies' played after the meal, to a full and packed dance floor, and guests were also kept extremely entertained and amused by the photo booth and all of its props!

FUNDRAISING UPDATES

Described as "The world's greatest road race route" the British London 10K is a popular race through the heart of London. Runners will pass a number of London iconic landmarks including the world's most famous clock, Big Ben. To run for SUDEP Action email fundraising@sudep.org. Places are limited so get in touch as soon as possible to secure your place.



If you would like to have a go at fundraising and you don't know where to start, please call Katie on 01235 772850, She's full of ideas!

Our evening was filled with so many emotions; happiness, sadness, laughter and tears. Just after midnight, everyone joined us as we released balloons to wish our little man a happy 14th Birthday. It was the perfect end to an evening we will never forget!

Over £10,000 was raised from the evening, and knowing that the money would help the WADD trials to go ahead made everything so worthwhile. Our next Masquerade Ball will be held on 31/12/2016!



It can be hard to think about writing a will. Many people struggle with the thought and keep putting it off, but facing up to the challenge can help us to help others. Please consider including us in your will. Call us on 01235 772850 if you would like to discuss leaving a legacy.

STRUGGLING TO COPE WITH GRIEF?

Have you experienced an Epilepsy Related Death?

Are you struggling with your day to day life?

Do you feel isolated and that nobody understands?

Do you feel angry or guilty about what has happened?

Do you have tortuous 'what if' questions going round and round in your head?

Are you struggling to find meaning and purpose in your life?

Or would you like to talk to someone?

If you answer yes to any of the questions above, why not give us a call on: **01235 772852** or Email support@sudep.org

Grieving is a normal reaction to the death of someone close, but if after some time those feelings disable you from managing your day to day life, or if they re-emerge after some time then you may benefit from speaking to someone from our support team.

The support team is here for everyone irrespective of when you were bereaved; time is irrelevant to us, everybody deserves support no matter when the death occurred. Our support service is tailored to your individual needs.



Speaking to someone soon after the death can be crucial especially after a sudden unexpected death as you may have many questions. Getting the right information at this stage can be vital.

When you have been bereaved for longer and feel that you can no longer talk to family and friends for many different reasons, we can help to fill that void. If you are supporting others this can be very exhausting and touch upon your own grief, looking after yourself is important; talking can help you do that.

There is no time limit to grief, don't go through this on your own; if you feel the need to speak to someone please call the support team. Email support and counselling is also available.