

#SpeakUp2SaveLives



SUDEP Action

Making every epilepsy death count

KEEPING IN TOUCH

Autumn/Winter 2021

HELLO THERE ...

Welcome to our news.

We have faced worse times before, as individuals and as a wider group. We know whatever you have been feeling, will be felt by many others across our community.

As you read in this newsletter, you will see how we have continued to give witness to all lives lost, and to present how this could be different if the whole system led the change that is needed, as we move through this pandemic to our future.

Our Lives Cut Short report, our Epilepsy Deaths Register study paper, and the latest from MBRRACE on deaths in women in pregnancy have been brought to the attention of our national leaders on patient safety and bereavement. We have increased our impact as risks have escalated.

We hope you will gain some comfort that we are continuing to make progress, we are propelled forward by the inspiration of families. Your stories, poems and creative outpourings are vital to our cause and help the daily work of the team.

SUDEP Action gives our thanks to all the supporters and donors who are so vital to our cause, and who have made SUDEP Action what it is today. Without you we would not be able to be here for people right now, when they need us more than ever. Your support is amazing and is helping to keep people safe. We continue to be here for you, too – stay well and pick up the phone or email – we would love to hear from you.

Jane Hanna OBE
SUDEP Action CEO

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HEALTH GRANT AWARDED FOR POTENTIALLY LIFE-SAVING EPILEPSY RISK COMMUNICATION RESEARCH



SUDEP Action, as part of a team of leading researchers, have been awarded a grant from the UK's largest health research funder, the National Institute for Health Research (NIHR) to investigate how best to have epilepsy risks discussions, that will have a positive and potentially life-saving impact.

In the UK, there are around 600,000 people with epilepsy (1 in 103 people). At least 87 people are diagnosed with epilepsy every day in the UK. However, 21 people with epilepsy die each week in the UK, many of them are young and otherwise healthy. Over 50% of epilepsy deaths are potentially preventable with better access to services and improved risk communication - which emphasises the need for effective discussions about epilepsy safety.

There is significant research showing the importance of communicating information about the risks linked to epilepsy deaths, including those linked to SUDEP (Sudden Unexpected Death in Epilepsy – when someone with epilepsy dies suddenly & prematurely and no cause of death can be found). Evidence-based tools are already freely accessible to support these vital conversations. However, there is limited research into how best to actually have these conversations, so that they make a

difference and help people with epilepsy to positively take actions to reduce their risks.

This study aims to identify and showcase best practice examples, to support future clinical discussions (& patient involvement in these) and produce guidelines exploring how best to hold conversations about risk. The NIHR have awarded the research team £151,199.00 to carry out this vital research.

Dr Cordet Smart (Research lead, University of Exeter), an expert in analysing the language used in conversations, will be heading up this exciting project. Supported by a research team including:

- Dr Rohit Shankar MBE, Consultant Neuropsychiatrist, Cornwall Partnership NHS Foundation Trust.
- Dr Craig Newman, Director, UXC.
- Sammy Ashby, Deputy Chief Executive, SUDEP Action (Lead Patient & Public Involvement)

Both Dr Shankar and Dr Newman already work closely with SUDEP Action as part of the SUDEP & Seizure Safety Checklist and EpSMon projects.

Dr Cordet Smart commented: *"Having the opportunity to lead on a project that could have*

real world impact for people with epilepsy is both exciting and humbling. I feel lucky to work with SUDEP Action who work so closely with people with epilepsy, their families, and bereaved families. This has enabled me to really connect with how important communication of epilepsy is. Conversation Analysis is a method of really understanding how communication works, and I am really hopeful that it will provide us with insights into how clinicians can best use language to have helpful conversations with their patients that will impact on people with epilepsy and their lives."

The project, started in autumn 2020, will record epilepsy risk discussions between clinicians and their patients. These recordings will then be analysed using a method called 'conversational analysis' to find themes and to identify best practice. The clinicians and people with epilepsy will also have a follow up interview/questionnaire

which will help support the analysis. The research team will then identify the best methods for sharing their findings with the epilepsy community to enable more effective, positive epilepsy risk communication.

Sammy Ashby commented, "SUDEP Action are delighted to be involved in this crucial project, and to have it recognised by NIHR as being important shows how recognition is increasing of the need to tackle epilepsy deaths through improved risk communication. With 21 epilepsy-related deaths each week in the UK, and nearly 50% of them thought to be potentially avoidable, action needs to be taken now to save these young lives. This project could bring us one step closer and will hopefully lead to better conversations between clinicians and people with epilepsy about risks. We know that knowledge saves lives, so now is our chance to prove it."

NEW EPILEPSY DEATH REGISTER RESEARCH IDENTIFIES RISK FACTORS FOR SUDEP IN CHILDREN

The Epilepsy Deaths Register (EDR) is one of the largest research data collections of epilepsy-related deaths, worldwide, built from reports by family members and healthcare professionals. Out of a collection of over 800 accounts and experiences, 46 incidences of definite or probable SUDEP, were identified for an in-depth research paper - representing the largest single group of Sudden Unexpected Death in Epilepsy (SUDEP) reported in children (under 16yrs).

This research looked closer at possible commonalities, like other illnesses or treatments, and circumstances near to the time of death.

SUDEP accounts for a large number of deaths in under 16s with epilepsy, yet there are still gaps in knowledge

about understanding the contributory factors that influence level of risk. Using anonymised data from the EDR, researchers from the UK and South Korea worked with SUDEP Action to identify and analyse **46 cases of SUDEP in children aged 1-16.**

Findings:

- **Concerningly, only a minority of family members completing the EDR were aware that people could die from epilepsy**
- **83% of those who died had been reported as being asleep immediately before the death. This is a strong connection, showing a need for surveillance during sleep**
- **41% of cases were reported to have conditions with neurodevelopmental disorders,**

supporting existing research that children with epilepsy and severe neurological conditions may be at higher risk of SUDEP

- A small number of cases of SUDEP were found in young people, without other illnesses, who were still awaiting their first specialist appointment.

(It is important to note from this that the risk of SUDEP is not restricted to those with a long history of seizures)

It is very important that the risk factors surrounding SUDEP are **understood and communicated** to people with epilepsy, and their families, early in diagnosis. Any epilepsy-related death is a tragedy with devastating consequences for those bereaved.

Understanding the risk factors is critical in the efforts to minimize the risk of lives being lost prematurely to SUDEP.

Other reports and findings from the **EDR research**, detail its progress since it was launched in 2013, looked at areas like the **Adult profile of SUDEP (2019)** and the **family experience after an epilepsy death (2018)**.

For an opportunity to get involved in research, SUDEP Action is currently conducting research into the impact of COVID-19 on those bereaved by epilepsy.

SUDEP Action is very grateful to all those people who have contributed their stories to the EDR to make this possible.

You can share your experiences with the EDR by:

Visiting www.epilepsydeathsregister.org and completing our online form. Phoning us on 0330 088 1220 or emailing team@epilepsydeathsregister.org to arrange an appointment to complete the form with us over the phone. Phoning us on 0330 088 1220 or emailing team@epilepsydeathsregister.org to request a hard-copy to be sent to you by post.

Do you want to get involved with SUDEP Action?

There are many ways you can get involved with the charity and help us with our constant fight to reduce deaths from epilepsy.

My Story - is an important and powerful way for you to join our campaign by sharing your story. Contact our Communications Team on - communications@sudep.org

Awareness and events - raise awareness by campaigning, volunteering, or attend one of our charity events - info@sudep.org

Fundraise - Celebrate the life of someone special whilst raising vital funds - fundraising@sudep.org

Your efforts, whatever you do, however active and however much you raise - makes a difference to what we can do.

We would love to hear from you.

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LATEST MATERNAL DATA SHOWS DOUBLING OF DEATHS OF WOMEN WITH EPILEPSY

A national enquiry has revealed the shocking finding that the number of maternal deaths of women with epilepsy has doubled in three years, during 2016 to 2018.

A key focus for this report is epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP) which "occurred almost twice as often among women who were pregnant, or in the year after pregnancy". It also discovered that "most women who died had clear risk factors for SUDEP but had not had risk or prevention measures discussed with them."

MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries in UK) investigated the maternal deaths of 547 women, who died up to one year after pregnancy, in a bid to improve the safety and care of pregnant women.



Key report findings:

- Twice as many women with epilepsy (twenty-two) died during or up to a year after the end of pregnancy in the UK and Ireland in 2016-18 from causes related to epilepsy, compared to 13 women in 2013-15
- SUDEP was the main cause of death for these women (15), though 2 drowned and 2 died due to status epilepticus (prolonged seizures). Exact cause of death was

not available for 3 women though they were known to have epilepsy

- 4 women were not taking epilepsy medications and very few women had documented pre-pregnancy counselling

The majority had uncontrolled epilepsy pre-pregnancy, less than half had specialist review during pregnancy.

It's evident that the vital conversation about person centred risk is crucial for those with epilepsy, and women need to have positive conversations about their choices if, and when, they become pregnant.

Advanced Clinical Practitioner, Kim Morley expressed 'extreme concern' about the pressure of the current COVID-19 pandemic on the NHS, which has already impacted existing neurology and maternity care provision. The epilepsy specialist midwife commented, "Out of all the deaths reviewed in the report, improvements in care may have changed the outcome in approximately two thirds of the cases."

SUDEP Action worked with MMBRACE on this report and is meeting Baroness Cumberlege (Chair of an independent review of families concerns about sodium valproate), and other national leaders this month to urge action across all deaths. Specifically for women, we are calling for rapid access to EpSMon and the Checklist and urgent changes to national policy and media communications.

OCT 2020 (SUDEP ACTION DAY) - BLOG FROM SUDEP ACTION CEO

It was lovely to join with over seventy other supporters to walk My Way To 5K for SUDEP Action Day 2020 as part of a week when we united with hundreds of organisations and many thousands of people all about #SpeakUp2SaveLives!

The My Way To 5K Walk was a wonderful moment after a busy week to connect again with so many friends and supporters of the cause who make all the work possible.



I chose a walk by a river with my daughter Kyra and our dog Woody. The river closest to us is the River Thames. I was brought up in the mountains and close to the sea so am drawn to torrents and waterfalls, but I love the strength and majesty of the River Thames as it makes its way surely and certainly to connect with our Parliament and to meet the Sea.

Kyra is learning maps, so we measured the 5-k distance on the map with a piece of string and a ruler which was just as well as Kyra's step counter didn't convert to kilometres!

In some ways a River walk was not the best choice. It was muddy to start with and as we reached half-way it started

to rain hard for the next 2.5 km. It made me think a little of the SUDEP cause!



The SUDEP cause has never been easy, but it is one that all in our community can take pride in. In the UK we have safety solutions and have created partnerships already in practice that need to be rapidly accelerated to give people the knowledge and the power to access what they need to reduce their personal risks. No amount of mud will stop progress.

We took shelter under a magnificent railway bridge. We can feel strength too from knowing that not only do we walk the walk to tackle deaths, but it is a walk on the solid ground of evidence alongside thousands of families who all have their own truth.

Like the bridge, we too have years of experience in overcoming physical distance and developing strong connections. When we sat down with Lucy Bidgood who developed the awareness walk alongside SUDEP Action Day, it only took a minute or two to come up with a plan about how we could overcome pandemic challenges and the My Way To 5K became a reality! It was a beautiful journey – the leaves

in greens, yellows and browns and the river full as we walked alongside. We were rewarded in the end by a wonderful rainbow just over the river. It also made me think of the SUDEP journey.

As Faye and Fraser shared their impactful blogs about raising awareness, I was reminded along the Thames that every *"small stone casts a ripple"*. I began my journey on my own and met four wonderful women. SUDEP Action today is thousands of people and there are hundreds of organisations that help whether that is a sharing of a tweet on SUDEP Action Day or relationships that have developed to an enduring partnership to save lives. One thing is certain – the pandemic like all the other barriers we have faced will not stop our river of change!

After an exceptionally demanding six months since the COVID-19 pandemic reached the UK, it was wonderful



indeed to take time to reflect. It is such an honour to walk alongside all the supporters of our cause during these times who are quite simply our heart and our engine room. My wonderful team at SUDEP Action, who make SUDEP Action Day and all our work possible, are tireless because of this.

Jane Hanna

KEY DATES FOR 2021

International Epilepsy Day (8 February)

Purple Day (26 March)

Online Epilepsy Memorial Day (5 May)

National Epilepsy Week (24-30 May)

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More exciting news and updates will be released soon. But if you would like to take part in any of the above events (online or offline), please do contact the office for ways you can get involved - 01235 772850 or info@sudep.org

FIDAN (AGED 51)

My mum Fidan was one of those people who were always full of life, with the biggest smile and love to give to everyone. What happened to her came as a big shock. Aged 51, with no medical complications, her life was sadly taken from her and us.

No matter what life threw at my mum, she had always overcome it. Being a strong single mother to two kids, she managed to stay as positive as she could. In particular, she enjoyed her dance classes, attending every weekend, then coming back and explaining it to us in detail. Her sarcasm and great sense of humour never failed to brighten up anyone's day. She was a genuine fighter, but this was one battle she did not win.

My mum had a seizure one morning, whereby miraculously, my brother heard her whilst asleep, and managed to call an ambulance. He said the seizure was so severe, he thought she was going to pass away - having not known anything about seizures, or ever seen mum sick, this was what he witnessed. An MRI was then booked for three months away (long period of time).

So, she was put on medication in the meantime... at no point were we told of the potential of SUDEP occurring. The medications were keeping her up at night, which is a risk factor for seizures in itself.

Therefore, she had her GP prescribe a new medication, of which he was going to increase the dosage over the next few weeks.

She was able to sleep and was well and happy, with just a slight fear it may



happen again.

Whilst I and my brother were out, she had another seizure.

I came home too late, to find she had passed away.

The cause of death, after a long investigation, was deemed to be SUDEP.

This was one of the first times we had heard about it. I still wish till this day, that if we were told about it by her GP, or Neurology team, that we could have taken precautions, or looked into it at least for the part where her medication dosage may have been too low.

I was 25 and my brother was turning 18 the week after she had passed away. The impact was heavy on our lives. Having the one parent growing up, whom we had never lived apart from at any point - to having no one in an empty home.

We appreciate our family and friends during this time, but the shock of it all is still there, especially when you are left with your thoughts.

On the brighter side, her name will live on with the jewellery brand that I have made. The brand also supports an

environmental cause, helping to plant trees ensuring reforestation, which particularly goes with the meaning of her name which is 'sapling', a young tree.

Having come across SUDEP Action, the charity has really helped raise awareness and money for a cause that is so close to our hearts. If we can

reach one person about the impact of epilepsy by sharing this story, then it would feel as if we have succeeded. Reading the stories on the SUDEP Action website has really helped us realise that we are not the only ones affected by this, and if my story can help someone feel this too, then I will be very happy.

Gulten (Fidan's daughter)

JANETTE (AGED 18)

It is still unreal to me that my daughter who was diagnosed with epilepsy at the age of 10, passed away from SUDEP on November 13, 2016. We had celebrated her 18th birthday just the month before.

I had stumbled across a short article about SUDEP two years prior, during one of my many searches for any information relating to Janette's intractable epilepsy. She was having more frequent seizures as the years went on, and additional types of seizures started occurring.

I miss her sweet smile, her sense of humour and wit, her loving heart.

Janette had goals she had set for herself and was accomplishing great things, despite living with epilepsy. She was a senior in high school, a feat I admired. The medications made it difficult for her to concentrate and caused a number of other learning challenges.

She was ready to take on adulthood, independently. She got herself a part time job; she looked forward to her senior prom and graduation. She was considering moving from the east coast



to Southern California, a place she truly loved. The vibe, the culture, the beaches, and the climate - she loved everything about it. Her family roots were in Southern California and she felt right at home whenever we went to visit family and friends there.

Janette was soft spoken with beautiful long dark hair and soulful brown eyes. She liked to draw, read, and she had a very soft spot for animals. She had a great laugh and the funniest sense of humour. She absolutely loved music and her baby nephew Joey. We spent a lot of our free time together, watching scary movies or grabbing coffee out, to catch up with each other about

our week. I was fortunate to have a teenage daughter who told me she loved me every single day. As her mother, her caretaker, and her best friend, I can't begin to express the sorrow and heartache I live with every single day since I found her. SUDEP took my precious girl; I miss her every second of every day.

She is survived by her brother Joseph and his wife Alyssa. There were many game nights, holidays, jokes, and love shared by them. Janette loved playing with her baby nephew, Joey, and reading Dr. Seuss books to him. My heart breaks for her sweet boyfriend Grady, and her best friend Clementine.

ISABELLA (AGED 16)

I lost my girl Isabella aged just 16 in June 2018.

It all started when she was around 7 years old. She kept falling over, then she would have these strange jumps, they increased to night seizures, which then increased to tonic-clonic seizures. After countless trips to the hospital, and drug after drug (that just did not work), our only hope was surgery. So, then we started all the tests that were needed.

All the time, she was getting worse, practically housebound for the last year of her life.

She denied having anything wrong with her, she would never say the word 'epilepsy'. She hated it all, the drugs, and the sheer hopelessness of it all. All she wanted was to be like all the other teenage girls, into makeup, snapchat and all the other stuff girls her age were doing, instead she was black and blue from all the seizures.

I'm hoping my beautiful daughter's short life was not in vain, as I donated her tissues and samples to medical research. I have high hopes that they will find something that may help other patients or neurologists in any way possible.

Please educate anyone you know who has any kind of seizure disorder about SUDEP. It is unfortunate that SUDEP isn't a standard conversation in the doctor's office. Not many people realize that there is a very real risk that your child, spouse, sibling, grandparent, friend...can die from this.

Margaret (Janette's mom)



The 15th June 2018 was a hot sunny day. I got a phone call from my son, Joe, to say he could not get in the house. So, I said I would ring Bella to let him in.

She didn't answer, so I texted her.

Again, no answer, so I was getting mad because I thought she was being awkward (she could be at times). I then left work to go home to let Joe in.

I went upstairs shouting for her to say 'why wouldn't you let Joe in?'.

I found the bathroom door locked and she had all her creams and potions she'd put on after a bath all laid out on her bed. My heart just sank - I knew.

I had to break down the bathroom door, and there, submerged in the bath, my beautiful 16 year old daughter Bella - gone from my life forever.

There was an inquest, September last year which confirmed the cause of death SUDEP.

I didn't let her have baths on her own when we weren't in the house, but she was stubborn, and just wanted to be "normal". She couldn't have a shower as that was too dangerous, she loved her baths, she didn't have much enjoyment in her life, so a lot of the time we would give in to her.

I'm glad she's not suffering anymore and she's free of the seizures.

But we all miss her so so much.

Carol (Isabella's mum)

ANOTHER DAY

Another day without you,
How will I bear the pain?
I thought maybe I had gained some strength
But today I am weak again.
Another day without you
And my tears just start to flow,
I gaze at your face in a photograph
And I ache for I loved you so.
Another day without you
Again ... I ask myself why?
How could you be taken so suddenly?
But now I am too numb to cry.
Another day without you
It's anger I'm feeling today,
I want to feel spirituality
But my faith is too shaky to pray.
Another day without you,
There's one thought that just might keep me sane
And that's if we move on to a better place...
Then I know I will see you again.



Eulogy by Irene Ellis in memory of her daughter Rebecca who died aged 20 in November 2000.

We understand that these My Story articles can stir up some memories and emotions of your own experiences.
If you need to talk, please do contact our Support team.
It's free and confidential.
support@sudep.org or 01235 772852.

GRAHAM LAYCOCK

In December we ran a socially distanced Christmas Grotto for 120 children in the village of Easton in Norfolk. Each family was given a 15-minute time slot, to adhere to COVID-19 rules. It took 4 days to erect and decorate the grotto, only for a gale to blow it down. Luckily, we were helped by a neighbour, providing us with a large bell tent and with help from other villagers, we were able to rebuild in a day. We managed to raise just under £800. Most was donated online through Clare's Remembrance page, while others donated directly to SUDEP Action.

I have discovered the best way for me to personally manage my grief, since losing my daughter Clare and granddaughter Charlotte to SUDEP, was to find something to keep myself busy. At the same time, I might also be able to raise funds for SUDEP Action and raise awareness of SUDEP to the public. Many villagers have not only been there to support my projects, but some have now also started to raise funds themselves for the charity. The latest being a month-long book sale

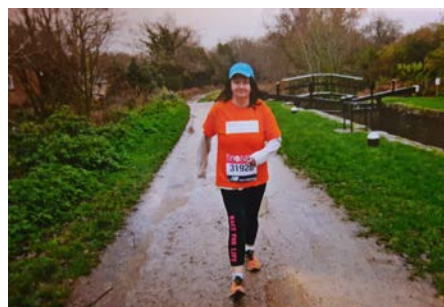


at a supermarket store, planned for March 2021. Plans are also being made for several more events to take place, hopefully not only raising funds, but more importantly more awareness.

As for the Grotto, every family has already forwarded their names for next year's.

ANNE O'NEILL

Thank you and well done to Anne O'Neill for raising £100 for SUDEP Action by completing The Virtual Great North Solo Run, 100.3 miles, in loving memory of her sister Brigid.



IAN INMAN

The family of Jack Rowlinson came up with some fantastic ways to raise funds over lockdown last year. As they couldn't have their annual charity event for SUDEP Action in October, they decided to run a family raffle to mark SUDEP Action Day.

The family make a very spicy hot pickle from a 4 generations old recipe. Friends and family love the pickle and flock to get some when they find out it has been made, so they decided to make loads to go along with the raffle and donate all proceeds. This decision along with a chance discovery led to some fantastic fundraising throughout the winter!

"The pickle sold well and the raffle, well our family loves a raffle anyway so that went mad too. The donation for SUDEP Action Day was £507. After the first donation of funds had gone in, people were still pestering for pickle Yvonne (Jack's Nanan) thought it may be a good idea to supply the demand and for the first time ever, to do a Christmas batch of pickle, ask everyone to pre-order, so we knew how many we needed, as well as run another small raffle. The pickle demand went barmy, everyone who had already had it, wanted more. We were having to post it to family members who were not local. Spending whole weekends chopping, peeling and cooking to supply the demand. The beginning of December came, all the pickle was distributed, the raffle sold and drawn, hence a nice second donation. Which we doubled ourselves, as the Christmas donation, which went in as £750.

On Saturday 19th December, the 6th anniversary of Jack leaving us. Yvonne was trawling the internet when she



came across a video clip of some "Santa Racing" which she then searched and found the website. She downloaded it and had a play, then showing it to me said "What about this?".

It was ace.

She suggested we ask a few of the family see if they wanted to brighten up a boring Saturday night and run a few races. She thought if we all pay £1.00 in per Santa, per race. Maybe have 5 races. Then pay half the takeout as winnings and donate the other half to SUDEP Action.

It was decided we could run it over a private messenger group streaming the races to all the friends and family added to the page. Before we knew it, in each race there was 50 Santa's running with a total of 5 races. It started a little subdued, but the fun soon kicked in when Jack's Grandad (Tig) started commentating on the races.

Nobody was safe from his tongue.

The end of the 5 races came, and by then everyone had loved the evening, and wanted more races. So, after a quick reshuffle, another 6 races were quickly put in place. We dropped the donation to 50p per Santa, per race to keep it affordable for the additional races. It was a massive success, some winners even leaving their winnings in

for an extra boost.

It had been so enjoyable everyone was asking if we would run it again Christmas Eve.

We gave it a little thought and agreed it was a good idea as no-one could go anywhere, and every penny raised for SUDEP Action was a bonus.

We decided to make it a full evening and we would run 12 races at 50p per Santa, per race (£6 for the evening). This time there were 65 Santa's all lined up and racing.

No-one could get enough of it as again at the end of the evening we were asked to run it once more, New Year's Eve. Unfortunately, that is Jack's birthday, so had to decline but agreed to do it New Year's Day night instead.

A quick one-off bit of fun soon turned into 3 full nights of fun.

New Year's Day we had to make alterations as Santa was resting up now after his hard work Christmas Eve, but we have now subscribed to the website and found loads of other themed races, so we ran 12 different races. We ended up with 66 races online that evening to run!

We have been asked to keep running the event from time to time so have agreed we will do so.

These race nights online over the 3 nights managed to raise an amazing donation of £805.00 from nothing.

Not bad for an accidental chance find on the internet by Yvonne of something that made her chuckle on such a sad day."

Ian Inman, Jack's Grandad

A GIFT IN YOUR WILL

To benefit those supported by SUDEP Action and to help reduce epilepsy risk

"To me, it will be a tangible way of saying a final thank you to an organization that has helped me continue my life following my saddest of days."

Gifts in Wills have been a valuable lifeline to SUDEP Action during the pandemic and have helped us keep our services running and conduct vital new research about the impact of COVID-19 on those living with epilepsy and those bereaved. If you would like to find out more about leaving a gift to SUDEP Action in your Will please contact the fundraising team on 01235 772850 or by email at fundraising@sudep.org. Gifts in Wills can make a lasting difference and can have positive impact on many people.

BOOKS WRITTEN BY SUPPORTERS

Maureen Lahiff

Maureen Lahiff, Vice-President of SUDEP Action and long-standing supporter has written a book. "Michael: A Transforming Presence" is about her son who had Down's syndrome and who she had difficulty accepting. The book opens at the bedside of his brother David who is unconscious, and brain damaged after suffering an epileptic seizure. Seeing his parent's tears, Michael picks up their hands, places them on David's hands then adds his own. This spontaneous physical connection becomes a treasured memory as they grieve for David after his death from SUDEP. Maureen goes on to describe how Michael contributes to many situations in meaningful ways, leading her to see Michael positively. She also reflects on disability, her faith, and her grief. Packed with information, people have said once they started reading it they couldn't put it down; also they saw people with disabilities more positively as well as being helped with their own grief.

The book is available from maulahiff@gmail.com £8.99 inc p&p and 50% of the sales of Maureen's book will be donated to SUDEP Action.

Sophie Pierce

SUDEP Action supporter and fundraiser Sophie Pierce is writing a memoir about the death of her 20-year son Felix from SUDEP.

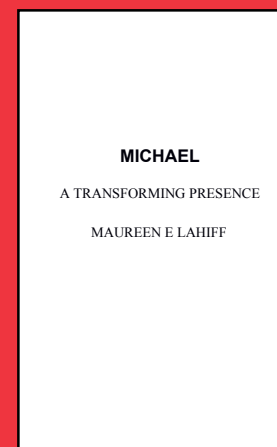
Felix, who was a student away at university, died in 2017. The memoir is called "The Green Hill: Letters to a Son".

Sophie hopes the book will raise awareness of SUDEP, as well as being a source of comfort to others like her, who have gone through the trauma of losing a loved one to SUDEP.

She says: "I found it enormously helpful to write letters to Felix after he died. It was a way of keeping my relationship with him going, as well as reflecting on what had happened. My memoir includes these letters, as well as a narrative telling the story of Felix's life and death, and how I dealt with this unimaginable loss. I hope it will be helpful for anyone who has suffered grief, which, let's face it, is all of us."

The book has been taken up by the crowdfunding publisher Unbound.

To support or find out more, visit: <https://unbound.com/books/thegreenhill/>



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In the quiet of the evening
I sit and think of you,
I open up my memory book,
Of the things we used to do,
And as I turn the pages,
My eyes are filled with tears,
For, although I have my memories,
I can't hold back the years.

A thousand loving memories,
Stored up in our hearts,
To take out and live again
Whenever the tears start.
We never lose the ones we love,
For even though they've gone,
Within the hearts of those who care,
Their memory lingers on.

Memory is a loving thing
It lasts the longest day
It can never be spent,
Never be lent,
Never be taken away.

~Anon

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SUDEP Action is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths, including Sudden Unexpected Death in Epilepsy (SUDEP). We are the only UK charity specialised in supporting and involving people bereaved by epilepsy.

Bereavement support:	support@sudep.org
Getting involved and campaigns:	info@sudep.org
Fundraising:	fundraising@sudep.org
Communications:	communications@sudep.org

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