



SUDEP Action 

Making every epilepsy death count

KEEPING IN TOUCH

Summer/Autumn 2020

HELLO THERE ...

Welcome to our news. I hope as you read this you and your loved ones are keeping well. We're facing difficult times together during 2020. We know you, our SUDEP Action community is resilient, that many of you have braved the worst – and in these uncertain times some may be braving even more.

You can read in this issue about the **Prevent21 Epilepsy & Behavior** special supplement '**Time to Listen. Epilepsy Mortality: Consequences & Solutions**' and that SUDEP Action services and safety tools have been endorsed as "best practice" by NHS RightCare and recommended by the LeDeR mortality review.

I have borne witness to tremendous acts of courage and self-sacrifice as people in our community have turned private pain, into public purpose, to make this possible. So, to the present, although the world has become a more uncertain place, as a community of people affected by sudden grief, we know all too well what it is like to confront an

unknown future. The poem by Joanna Fuchs on the back page of this edition is testament to that.

It is a great tribute to our movement for change that SUDEP Action was able to partner during lockdown with the University of Oxford and Newcastle University **to undertake research surveys on the impact of COVID-19** on people with epilepsy, carers, health workers and bereaved families. With close to 2,000 participants now, this is already telling us that our prevention work and bereavement services are more vital than ever. SUDEP Action has been able to be alongside suddenly bereaved families during the most traumatic of situations because our strong community of bereaved families have shared their experiences.

If you or anyone you know would like to be part of this unique and powerful research, please contact Vicky on info@sudep.org or 01235 772850 to request a call to complete a survey, or a postal survey.

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During this period, we want you to know that we will continue to make a difference in these times of great uncertainty. While we may not have all the answers, we do have a plan to emerge safe and strong so we can always be alongside families. SUDEP Action saw a collapse in all fundraising face to face events after lockdown and moved urgently to our emergency plan. We have been fortunate so far that people and companies who were personally connected to our cause came to the rescue of the charity as did our dedicated team who volunteered salary reductions.

So, 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 wouldn't be able to be here for people right now, when they need us more than ever. Just knowing that you are there helps our team to do their job every day to the best of their ability. Your support is amazing and is helping to keep people safe. We continue to be here for you, too – stay well and be in touch.

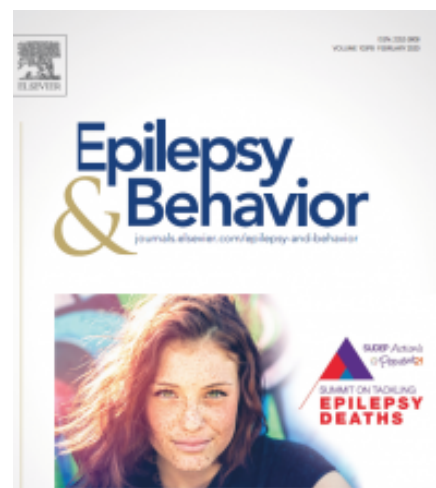
Jane Hanna OBE
SUDEP Action CEO

INTERNATIONAL JOURNAL PUBLISHES UK RESEARCH ON TACKLING EPILEPSY DEATHS

Key research from SUDEP Action's landmark **Prevent21 Summit**, has been published in a leading international epilepsy journal, **Epilepsy and Behavior** – sharing expertise and recommendations from the event with clinicians and researchers worldwide.

The special supplement '**Prevent21 Summit – Time to Listen. Epilepsy Mortality; Consequences and Solutions**' contains 12 papers highlighting key research on what is, and can be done, to prevent future epilepsy-related deaths, as well as what is needed to better support those bereaved by epilepsy in the aftermath of a death. Each research paper has been written by leading experts who participated in the first Prevent 21 Summit, including SUDEP Action's very own Jane Hanna OBE, Karen Osland, Sammy Ashby, Tracy Cowdry and Julia Stirling.

The Prevent21 Summit was held in Oxford in November 2018. 71



specialists in epilepsy, neurology, bereavement, health services, policy making, and the justice system attended the event; representing 43 different organisations. All working together to agree on recommendations and actions needed to prevent future epilepsy deaths.

CALL FOR URGENT ACTION AS LEARNING DISABILITY MORTALITY REPORT HAS EPILEPSY IN THE SPOTLIGHT



Learning Disabilities Mortality Review (LeDeR) Programme

Epilepsy deaths have been flagged as a significant concern in the latest LeDeR Review which looks into deaths in people with learning disabilities. LeDeR (**Learning Disabilities Mortality Review**) is a national review programme aiming to improve the lives of people living with learning disabilities by learning from deaths and reviewing care.

The **2019 LeDeR annual report** was published in July 2020 and highlighted:

- Epilepsy was the sixth most frequently recorded cause of death in people with learning disabilities in 2019 and 2018, with more adults and children dying in 2019 compared to in 2018
- The highest number of deaths was in those aged between 4-17 years old
- Epilepsy was also the second most frequently reported potentially treatable cause of death

The report made the recommendation that the **SUDEP and Seizure Safety Checklist (for clinicians)** and **EpSMon app (for people with epilepsy)** should be used as a safety measure for people with epilepsy. Echoing the **NHS RightCare Epilepsy Toolkit** which cites these tools as 'best practice' for taking a risk management approach to epilepsy mortality.

The report also recommended a minimum of an annual epilepsy review (and up to date care plan), as

well as improved training for people with epilepsy and their carers around issues such as emergency/rescue medications.

Jane Hanna OBE, SUDEP Action's CEO commented *"It is shocking that 18 years after the National Audit found serious failings in epilepsy risk management in people with learning disabilities, that this 2019 mortality report finds epilepsy as the second most frequently reported treatable cause of death in people with epilepsy and learning disabilities. What is hopeful is that SUDEP Action's safety tools are recommended."*

Now we are looking for actions, not just words, from Governments and their agencies; they must raise their game and do all they can to prevent future deaths"

Standardised use of the **SUDEP & Seizure Safety Checklist** to support epilepsy risk communication between clinicians and their patients (and carers) **has shown to help reduce risk in people known to be at risk.** The free award-winning tool is currently used by nearly 1,000 clinicians across the UK.

EpSMon, the free app for people with epilepsy, also supports these important discussions by enabling people to monitor their epilepsy, risks and wellbeing in-between medical appointments so they can seek help sooner if risks are rising or their epilepsy is negatively changing.

LOCKDOWN BLOG FROM VICKY, COMMUNITY SERVICES SUPERVISOR

As many of our supporters will know, at the beginning of lockdown due to the COVID-19 pandemic, the SUDEP Action staff all agreed, that some of our team would be on furlough and others agreed to make a temporary pay sacrifice for the coming months. This was so that we could continue to be here for all our supporters, bereaved families and clinicians during what has been and continues to be an incredibly challenging time.

When I was initially furloughed in May, I think like a lot of people, I spent a few weeks feeling quite fearful, watching a lot of news and generally trying to get my head around the extraordinary change to life we were all facing. As time went on I realised that too much news was perhaps not doing my mental health much good.

I missed my work, the SUDEP Action team and being in touch with our families, supporters and professionals. I thought and wondered often about the impact that hearing every day about unexpected deaths around the country and world, could be having on bereaved families already having to deal with so much. I decided that I wanted to find something to fill my time that would help me keep my mind active but could also help me in supporting families when I re-joined the team.

I found a Grief and Bereavement Counselling Diploma and worked on this during my two months furlough and was pleased to gain the certificate this week...with distinction! It helped to underpin my existing training and



work as part of our experienced and specialised support team led by Tracy. One of the main points that ran through the research and I recognised well from working with our bereaved families, was that there is no right or wrong way to grieve. As individuals we all must do this our own way but that in support of each other, we don't need to do it alone.

Vicky Masters-Read
Community Services Supervisor

SUDEP ACTION SERVICES RECOGNISED AS BEST PRACTICE IN NEW EPILEPSY TOOLKIT

NHS RightCare: Epilepsy Toolkit Optimising a system for people living with epilepsy

In England, people living with epilepsy and the systems supporting them are experiencing challenges including high misdiagnosis rates; inaccurate epilepsy population estimates; increasing mortality attributed to epilepsy and a lack of optimal management strategies that could reduce unnecessary emergency care for people living with epilepsy.

On 13 February, **NHS RightCare** has published a new Epilepsy Toolkit which will support health teams and service providers to better understand priorities in epilepsy care and key actions to take to improve outcomes and quality of life for those with the condition.

SUDEP Action, alongside representatives from Young Epilepsy, Epilepsy Action and clinical experts from across the country have been involved in creating this toolkit with NHS RightCare.

The Toolkit aims to support local healthcare providers to understand, improve and develop their services for people with epilepsy by:

- **Providing statistics on why action should be taken to improve epilepsy services locally**
- **Signposting local providers and clinicians to 'best practice' information, tools and resources to support their work.**
- **Recognising the role charities and other organisations play in supporting people with epilepsy, their families, carers, clinicians, and those bereaved by the condition**

The Toolkit dedicates a whole section to 'taking a risk management approach to [epilepsy] mortality' – highlighting

the importance of understanding and taking action against epilepsy deaths to local and national health services and clinicians; some of which may be unaware that epilepsy can be fatal.

SUDEP Action's core services have been recognised as best practice examples for 'taking a risk management approach to mortality', including our free:

- **SUDEP & Seizure Safety Checklist** for clinicians to discuss and review epilepsy risks with their patients so potentially life-saving interventions can happen
- **EpSMon app**, helping people with epilepsy to quickly monitor any changes to their condition and wellbeing in-between appointments
- **Epilepsy Deaths Register**, helping learn vital lessons from information shared on epilepsy deaths by involving the bereaved in research
- **Specialist support and advocacy service** for anyone bereaved by epilepsy; early signposting to the only UK epilepsy bereavement service can provide urgent help with coroners/inquest, and free counselling and support
- **Information and advice** for those living with epilepsy, their families, carers, clinicians and for the bereaved

Samantha Ashby (Deputy Chief Executive) who represented SUDEP Action and their bereaved supporters in the creation of the Toolkit commented, *"SUDEP Action recognises first-hand the importance of the core to this toolkit - taking a risk management approach to mortality. The best practice examples highlighted in this toolkit, show significant potential for change and many opportunities for local services address the inequalities and variation facing their epilepsy community; helping people with epilepsy to live well, for longer. We hope the publication and use of this toolkit will provide support to make this possible, so that future lives will be saved."*

Why is the Toolkit needed?

In England, people living with epilepsy and the systems supporting them are experiencing challenges, including high misdiagnosis rates; inaccurate epilepsy population estimates; increasing epilepsy deaths, and a lack of strategies and access to services that could reduce unnecessary emergency care. There is also significant variation in epilepsy services depending on where you live.

With at least 87 people diagnosed with epilepsy every day, and 21 epilepsy deaths each week in the UK (nearly half of which are thought to be avoidable), the NHS RightCare Epilepsy

Toolkit has been developed to highlight the need to local healthcare providers to do all they can to support people with epilepsy, despite it not being a national NHS priority.

By creating a toolkit looking specifically at the challenges and opportunities for epilepsy care, it helps local healthcare providers to review their current epilepsy care and services and to find opportunities for improvement, which in some cases could save lives and better support those bereaved by epilepsy in the devastating aftermath of their loved one's death.

Sammy Ashby continued, *"People with epilepsy are at increased risk of dying suddenly and prematurely – causing significant grief and trauma throughout communities. Nearly half of these unexpected deaths are potentially avoidable, with improved access to information, services and better risk management. It is wonderful that NHS RightCare recognise how vital it is for regular risk communication, as well as signposting people to specialist services after a death has happened."*

Now the Toolkit has launched nationwide, the next step is to make sure those providing existing or commissioning new epilepsy services know it exists, and to support them in using the wealth of information in the toolkit to improve and hopefully save lives in their local area.

INITIAL IMPACT RESEARCH FINDINGS ON THE AFFECTS OF COVID-19

The pandemic has brought significant change to the epilepsy and third-sector communities. As a charity specialised in supporting those bereaved by epilepsy, and dedicated to preventing epilepsy deaths, our funding evaporated when UK lockdown hit. Our small team had to quickly develop new ways of meeting the increased demand on our services, with fewer resources; made more challenging by receiving no Government support.

Despite this, SUDEP Action launched three research projects to understand the impact of COVID-19 on people with epilepsy and their carers, healthcare workers, and on those bereaved by epilepsy. As the more we learn, the better we can support these communities to hopefully reduce risks, improve wellbeing and save lives.

Working alongside the University of Oxford, and supported by international researchers and clinicians, our epilepsy risks surveys have received over 1,250 responses worldwide. Initial findings show an alarming rise in epilepsy-mortality risks and marked disruption to epilepsy services. 34% of people with epilepsy reported changes to their health since the pandemic began, mentioning worsening mental health, concerns over other health conditions, and sleep difficulties. A third of those reporting health changes also saw worsening seizures:

"I am not currently being seen by my specialists...it's worrying. I would have to travel to London for treatment... Also, shortages/slow prescriptions are scary too - as I go into status if I don't have them. I'm worried the stress will bring on a big one...My seizures have been much more frequent too"

Of the patient respondents, only 14% say they'd had SUDEP (Sudden

Unexpected Death in Epilepsy) discussions with their Healthcare workers, despite changes in their epilepsy and risks.

For many, these changes occurred in a context of reduced epilepsy services, with 26% reporting difficulties in receiving care. We are also seeing an impact on their wider lives, with concerns shared about finances, employment and access to key resources (eg: food, prescriptions and transport).

Epilepsy healthcare workers reported they now increasingly use teleconference clinics, though 79% state they're not as confident in managing patients this way. Many also expressed concerns about diagnosing patients currently. Concerns were also expressed that patients may not be engaging with their services, even if their epilepsy is worsening:

"We are wondering where have all the patients gone, and so you have a legitimate concern that patients might not be reporting...and might not make an appointment for an annual epilepsy review."

The statistic of most concern is that only 44% of UK healthcare workers report discussing SUDEP with patients. Also, alarmingly 6% of Healthcare workers reported never discussing SUDEP, despite it being a national guideline recommendation since 2002.

At a time where services are remarkably different and distant, and where people with epilepsy are reporting rising risks – consistent, comprehensive epilepsy risks and SUDEP communication is vital. SUDEP Action's free risk communication tools, the SUDEP and Seizure Safety Checklist and EpSMon app help bridge this

*Keep Friday 23rd
October 2020 in
your diary. We'd
love for you to be
involved in this
year's global event.
More details will
be released soon.*



communication gap, flagging if urgent support is required. We urge epilepsy risk communication becomes national standard practice, both now and post-pandemic.

From our work supporting hundreds of people bereaved by epilepsy, we have heard how the pandemic (& UK Government lockdown) is taking a toll on their grief. Our research with Newcastle University and the Epilepsy Deaths Register highlights the extent of this impact and the complexity this adds to their lives.

Over half of the 270 bereaved who shared their information experienced worsening sleep and have thought more about the person who died since the pandemic began. Overwhelmingly they felt their mental health had worsened, some experiencing more flashbacks and increased guilt over their loved ones' death.

During my time in isolation it was my son's birthday. For the first time in 16 years I was not able to go to his grave to put fresh flowers or celebrate his life in any way...It was heart-breaking, like I had forgotten him, although this could never happen..."



Despite these negative impacts on their wellbeing, 67% reported difficulty accessing support networks. Feelings of isolation are common, and the impact COVID-19 has had on people's usual ways of coping is immense.

The pandemic is far from over and its ripple effect will continue for some time. Yet it's vital people with epilepsy are not left at risk and uninformed about how to self-manage their epilepsy and reduce risks. Resuming 'normal' epilepsy services promptly is crucial to provide support and expertise to help keep people safe. As those bereaved by epilepsy know – the cost of not getting this right can be far too high, pandemic or not.

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.

SUDEP Action
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CHRIS T

My son Chris was a bright, lovely child when he was growing up. Always curious and thinking about things and how they worked. People often said he was like a 'little old man' as he often responded in an adult manner way beyond his years.

He showed a great interest in how people's minds worked and asked for his first psychology book at 11 years old!

Chris had his first epileptic seizure in January 2016, when he was 15 years old. It was a nocturnal tonic clonic seizure. He was taken to hospital, but no one expressed a great deal of interest in one seizure.

In September 2016, he had his second nocturnal seizure and was referred to the neurologist who prescribed medication. Chris was studying for his A Level's and found even on low doses the medication caused him memory and cognition problems. He returned to the consultant who prescribed alternative medication. He was still worried about the effects this might have on his studying and as he only experienced 1-2 seizures a year he decided to stop the medication.

The hospital made no further contact with him, there were no suggestions for further monitoring and no mention of SUDEP.

Chris continued to have 1-3 seizures a year, it became obvious that they were exacerbated by emotional stress and anxiety. Chris and I discussed medication during this time, and he said he felt his epilepsy was not a problem.



I had helped Chris complete the paperwork for him to be able to access the DSA for extra support.

We talked about university and the change in lifestyle, and we saw a neurologist in the new area we had moved to. Chris and I agreed that medication at this point was probably a good idea.

The neurologist was about to prescribe different medication, but then said he was not convinced it was epilepsy. He thought it might be 'non epileptic seizure disorder'. As he said the seizures had started during a very emotionally traumatic period in Chris' personal life. He decided not to issue the medication pending an EEG and wanted Chris to return in September 2019.

Chris was offered a place through clearing to study Psychology at the University of Sussex. He was over the moon that finally his dream was becoming a reality. I was then in the process of trying to set up additional safeguards such as mattress sensors and a seizure wrist sensor. Clearing students weren't guaranteed on

campus accommodation, but due to his epilepsy and some determination we secured him a place on campus on 28th August.

Chris and I had arranged to go and see the University of Sussex on 31st August and stay overnight in Brighton to explore. Chris never made this trip, as on 30th August 2019, my sister found that Chris had passed away in his sleep during the night.

The post mortem cause of death came back 13 weeks later, as SUDEP. I cannot find the words to describe the loss of my son; it feels as though my heart and soul has been ripped away and I have lost the person in my life that I loved the most, and greatest friend I had ever known.

We are all devastated at the loss of such a kind, caring and intelligent young man who had a bright future ahead of him. We have collected for Young Epilepsy and we are currently collecting to try and raise enough money to train a Support Dog for someone with epilepsy/disabilities and we are hoping to name the dog Chris, in his memory.

I did research epilepsy after Chris was diagnosed and each of the main websites stated that SUDEP was an uncommon event, and more likely to happen to people with uncontrolled frequent seizures. Chris' 1-3 seizures a year were not considered frequent. SUDEP was never mentioned, and the

main worry seemed be about falling and hurting themselves or getting stuck in status epilepticus.

I know now that the risk of SUDEP is not just likely to occur to people with more frequent seizures, it can happen to anyone with epilepsy.

I feel that professionals should advise everyone diagnosed with epilepsy about the risk of SUDEP in **anyone** who has epilepsy. A risk assessment should be completed with their risk highlighted and this should be updated at regular intervals, or if there is a change in their seizure pattern. This information is not meant to scare people, but it does allow them to be fully informed of the risks involved and what to do to minimise these risks.

We might have made a different decision had we been given the full information; as Chris and I could have made the decision to persevere with the medication, until a reasonable medication with tolerable side effects had been found. We might have questioned the neurologist's decision not to issue the medication, but in all fairness, I believe that there is a lack of an awareness of the true risk of SUDEP within the clinical profession. We will never know now whether this would have made a difference, and Chris would today have been studying at university, instead of us grieving the loss of this wonderful young man.

Bev (Chris' mum)

BEN

Benjamin was born on Christmas Eve 1989. We were so happy to welcome him, and his sister Charlotte was happy Father Christmas had left her a baby brother.

When he was around 18-24 months, he was diagnosed with autism. He was the happiest little boy, and we decided nothing would ever change our mind about that.

As he turned about 12, he developed epilepsy. We started seeing neurologists, and he had scans, but we were never told he was at risk of dying. By anyone.

Ben went through many changes of medication, until we finally thought we had found the right ones. On 13 December 2016, Ben saw his neurologist, who was so pleased with his progress, she decided he could be seen in 12 months' time.

On 23 February 2017, I went to wake Ben for his meds at around 8am and found my beautiful boy lifeless. I tried CPR, and the Paramedics took over for around an hour.

We were told he had not had a seizure, and they had tried everything to revive him. We are so thankful that he did not suffer. But not being told he was at risk



of SUDEP made our anger and pain so much worse.

Nothing can ever describe the pain and devastation of losing a child. Ben was the sunshine of our days, and now he is the starlight of our nights. His sister Charlotte and her children miss him beyond belief.

Ben's Dad Chris is loved by the football community, so they started a charity match, to be played in Ben's memory every year, to raise funds for SUDEP Action, and autism awareness. We are so grateful to our friends who have supported Ben's memory and given us support too.

He was a gentle giant when he left us (6'6"!), and that is how our village remember him. Our beautiful gentle giant, Ben... "To Infinity, and beyond!"

Chris & Mel (Ben's parents)

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.

HAYDEN

My son was my second child. A much wanted younger brother to Georgina. Born in England, he grew up in Wales and considered himself to be a Welsh man.

Hayden had a difficult start, he was born with hydronephrosis that required surgery. He had his first seizure at six months old, but it was put down to febrile convulsions. Many seizures later, at the age of eleven, he was finally diagnosed with epilepsy and started on medication. No medication made a difference to his seizures. But one medication changed his personality. He went from a caring, loving, accidentally funny and clumsy young man to a moody angry aggressive person. We wasted a year of his life on that medication, not seeing the change in him as a result of the pills, but as him being at fault. I regret that.

He had a fantastic imagination making up stories and he became a devoted big brother to his little sister when she came along. He loved history and was an avid reader. He had a dog, Pepper. She and he were made for each other. She loved him and he loved her. She died two months before Hayden. Hayden had dreams of seeing the world and writing a book. He wanted to be a librarian, or history teacher. Epilepsy took over his life, seizures increased with puberty, to a point that he would have on average three a fortnight. He also had complex partial seizures and absences.

Hayden became isolated when his epilepsy resulted in him being asked to leave his course at college. So many people have said how highly thought of



he was. It's hard that he never knew. Hayden joined a group of volunteers taking dogs to care homes. He used his grandparent's dog for this as Pepper was slowing down. He felt so guilty every time he left her behind and would bring her treats to make up for it. He took her everywhere he could, and she, though never officially trained, stayed by his side during seizures and would bark to get attention if she thought no one else had noticed. She gave him confidence to go out without anyone else.

His last day was spent making a fuss of me as it was my birthday. He was last to bed that night and it is unclear whether he made it upstairs at all. He died downstairs alone. I found him the following day. He was face down on the floor, it was clear he had had a seizure. My daughter and I tried to save him knowing really that it was too late. The first time I heard SUDEP mentioned was by one of the first responders who said to his colleague just that word, and a look between them. Hayden was twenty years old and had never been told he was at risk, or that SUDEP was a thing. This needs to change.

During his childhood, he was seen by a paediatrician only, who never

prioritised his epilepsy. Time was wasted that should have been spent trying to find an effective treatment, wasted talking about his weight and his suspected autistic behaviours. Epilepsy was always the last thing mentioned at the end of the appointment. It was given no importance, and no action plan was ever discussed. Once he moved to adult services and met his neurologist, we finally felt like he had a chance of getting it under control. He simply didn't have enough time.

Hayden's death has been attributed to SUDEP. We set up a Much Loved memorial page for Hayden, raising money for SUDEP research, Epilepsy Action and the Muir Maxwell trust. The last charity gave Hayden a bed alarm when he started having night-time seizures. Because of his relationship with his dog Pepper, I've decided to sponsor a dog through Support Dogs charity, to be trained as a support for someone with epilepsy. I did it to mark his birthday, and plan to do it every year.

Helen (Hayden's Mum)

A GIFT IN YOUR WILL

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

A gift in your Will helps SUDEP Action continue to support all those bereaved by epilepsy who need us and enables those living with epilepsy to access potentially life-saving tools and information.

Making a Will is easy. For a small fee, a qualified legal professional can do this with you and ensure that your estate is inherited by your chosen beneficiaries, including charities.

"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."



If you would like to find out more about how leaving a gift in your Will, to SUDEP Action, will provide lasting benefits - please contact our fundraising team by phone on **01235 772850** or by email fundraising@sudep.org.

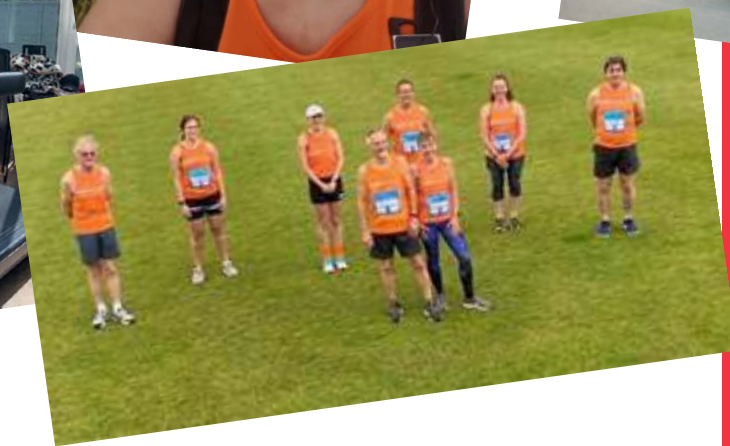
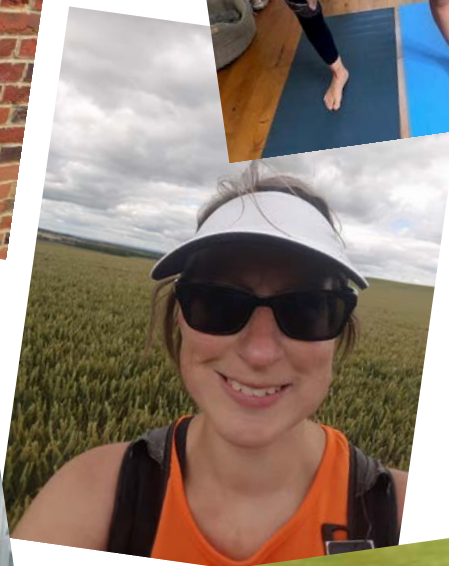
To find out more about our special discounted Wills offer with Co-op Legal Services visit our website <https://sudep.org/gift-in-will>

Gifts in Wills, whatever the size, make a big difference

**REMEMBER US IN
YOUR WILL**
Help our work live on...

SUDEP Action is now part of Recycling for Good Causes. If you would like to recycle to support SUDEP Action you can use the envelope enclosed for small items, or contact us on 01235 772850 to request a freepost label for larger packages. Details can also be found on our website <https://sudep.org/recycling-sudep-action>. Every recycled item will make a difference. Thank you!

Thank you to everyone who took part in a fundraising event over the UK Lockdown, helping to raise much needed funds for SUDEP Action. Your challenges included virtual runs, Prevent 21 Challenges, 2.6 Challenges and doing your own great events.



If you are thinking about taking part in a fundraising challenge please get in touch. We can help you with advice, materials and information. You can call us on 01235 772850 or email fundraising@sudep.org

SUDEP Action

If we could bring you back again,
For one more hour or day,
We'd express all our unspoken love;
We'd have countless things to say.
If we could bring you back again,
We'd say we treasured you,
And that your presence in our lives
Meant more than we ever knew.
If we could bring you back again,
To tell you what we should,
You'd know how much we miss you now,
And if we could, we would.

~ Joanna Fuchs



SUDEP.ORG

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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