



## SUDEP Action

*Making every epilepsy death count*

## KEEPING IN TOUCH

Winter/Spring 2019

### HELLO THERE ...

A heartfelt thank you to all for your help in 2018.

Let's recap on some milestones we achieved together.

SUDEP Action has helped over 11,500 people in the last year, and because of the success of the Prevent21 campaign, are already doing more.

We have reached thousands of people with epilepsy through the EpSMon app. Yet many of these were people who report into/ use EpSMon, show they are at risk, and also report that they were not having their epilepsy reviewed or checked by a health professional. Our SUDEP and Seizure Safety Checklist is increasing in popularity as a tool with nearly 650 health professionals having registered to

use it since its 2015 launch. Recent feedback on the Checklist from clinicians using it, showed it having a positive impact: "A valuable opportunity to assess and address risk issues associated with epilepsy".

Your support has also meant we have been able to influence Government. Our Call to Action in February 2018 and our UK Prevent21 Summit in November, have spurred support from a broad movement, led by SUDEP Action, to tackle deaths - and we are being heard.

The release of the Public Health England report on rising deaths in people with neurological conditions, quietly onto a website, angered many. By the summer, the Department of Health was responding to media questions with talk of new guidelines, being the answer to deaths!

**SUDEP.ORG**

But with the help of the BBC and other national broadcasters, we saw the message change again. We were pleased when we met with senior policy makers and the Chair of the Health Select Committee, that there was news of a new workstream in NHS England to include epilepsy. This is good, but is still not nearly enough – how can it be when at least 21 people are dying every week?

We called in the summer for a funded annual review and risk check for those with epilepsy. We will also continue to push for epilepsy to be included in the Government's new 10-year plan for the NHS.

This was just one of the recommendations from supporters attending our National Conference in July. Learnings from the experiences of bereaved families on the Epilepsy Deaths Register and from research, were also centre stage of the Prevent21 Summit held in November; attended by over 70 experts and 43 organisations. If Government supports epilepsy in the NHS 10-year plan and include the recommendations from the Prevent21 Summit report, we could speed up the pace of change. This report has been endorsed by the All Party Parliamentary Group for Epilepsy (APPG) and The Neurological Alliance.

The findings from the Prevent21 Summit will also be published in a special supplement in

the Journal 'Epilepsy and Behaviour', in 2019. In the meantime, we are moving ahead with actions 'on the ground' to help fill the painful gaps. Thanks to your help through the Prevent21 campaign, for the six months between April to September 2018, our donations and fundraising income was 77% more than in the same period in 2017.

At a time of great uncertainty nationally, we are really pleased to say that we remain positive and able to push forward. For now, we were thrilled to develop a collaboration with Newcastle University, who join us in our work on the Epilepsy Deaths Register. Their report on over 500 UK deaths is used by us to influence change, most recently informing the Ministry of Justice on how to improve the experience of families that are caught up in the coronial system. This included the help we have been able to offer families this year, with an integrated support service, including a case worker.

With your help we continue to grow and can do more. In Spring 2019, we will be moving to an office in Wantage that will help us to that. We also have some very positive announcements for 2019, which I look forward to sharing with you soon.

**Jane Hanna OBE**  
**Chief Executive, SUDEP Action**

## SUDEP Action new address

18 Newbury Street,  
Wantage,  
Oxfordshire,  
OX12 8DA  
01235 772850

## EPILEPSY MEDICATIONS WILL BE EXEMPT FROM BREXIT AFTER COALITION INTERVENES



**The Sunday Times reports Serious Shortage Protocol for medicines will not apply to epilepsy, after epilepsy coalition intervenes to protect patient safety, but campaigners warn we need plans public and in writing.**

A coalition of epilepsy, neurology organisations and the All Party Parliamentary Group for Epilepsy, who predicted rising deaths from use of a Serious Shortage Protocol for medicines (**The Sunday Times, 6th January 2019**) call on government to make a clear statement regarding their medical contingency plans for epilepsy and neurology, after **The Sunday Times reports epilepsy will now be excluded from the protocol.**

In December 2018, it emerged that in the event of serious drug shortages, the Government has plans to use **emergency powers to authorise pharmacists** to overrule medical prescriptions.

The leaks to The Times (7th December 2018) and an 'informal private consultation' by Government on a draft Serious Shortage Protocol' which included epilepsy, raised anxieties across patient organisations. Expressing concerns about the risks to patients if the proposed protocol was to go ahead, allowing pharmacists to overrule medical prescriptions in the event of a national medical

shortage. On 21st December 2018, the Government published its **EU Exit Operational Readiness Guidance** including a "Serious Shortage Protocol" that would involve changes to medicines legislation.

Epilepsy affects over 600,000 people in the UK, and people with epilepsy risk developing new seizures if their usual medication is altered. Although, for some medications a change in version is not risky, but substituting a different version of many epilepsy medications, risks breakthrough seizures and side-effects. There are 21 epilepsy-related deaths each week, many in the young. This planned contingency measure has the potential to make matters worse. **We predicted unnecessary deaths resulting from the use of these powers.**

A letter was sent to Matt Hancock MP, Secretary of State for Health and Social Care, on 21st December 2018, calling for action to address the likelihood of medicines shortages in the near future and expressing concerns about the Serious Shortage Protocol.

The coalition letter was sent to The Sunday Times on 3rd January 2019, calling again for the Government to rethink the plans that have been shared with the sector and urges full openness and scrutiny of emergency planning.

The Sunday Times has since reported (Sunday 6th January 2019) that the Government will exclude epilepsy from the Serious Shortage Protocol, following the request for a response to our letter.

Jane Hanna OBE, Chief Executive of SUDEP Action, who led the coalition said:

*"Whilst we welcome hearing from The Sunday Times that the planned protocol will not include epilepsy, it begs the question about other neurological conditions and what alternative contingency there is for conditions, like epilepsy, that will be excluded. We urgently need a statement from Government on what assurances ministers can give at this time about continuity of supply of essential medicines."*

Following the Prevent21 Summit, SUDEP Action has forged a coalition of

epilepsy organisations (Epilepsy Action, Epilepsy Research UK, the British Branch of the International League Against Epilepsy and the Epilepsy Specialist Nurses Association), The Neurological Alliance and the All Party Parliamentary Group for Epilepsy.

**What can I do if I am concerned about my medication?**

If you are concerned about your epilepsy medication, there are number of things you can do:

- **See your GP** - we would always recommend that you have a conversation with your prescribing clinician, about your medication concerns
- **Contact any of the epilepsy patient helplines available**
- **Support this coalition and write to your MP.** Visit our website to download our template letter which you can personalise.

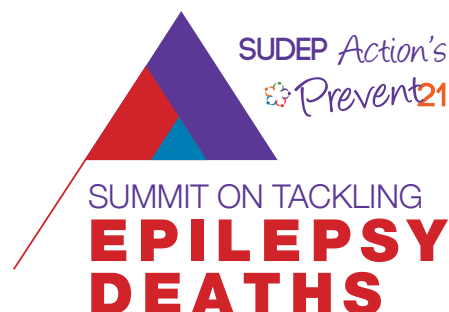
## SUDEP ACTION'S PREVENT21 SUMMIT

SUDEP Action held the first national Prevent21 Summit on 2-3 November 2018, to tackle urgent issue of rising epilepsy deaths.

Over 70 representatives across health, political, educational and allied epilepsy organisations, gathered for the two-day event at Corpus Christi College, Oxford.

21 people die every week in the UK from an epilepsy related death and reports show that 42% of these deaths are potentially avoidable with things such as improved access to services and information, and better risk management.

The Prevent21 Summit enabled key UK influencers and policy-makers to meet, discuss and find ways of collaboration to help prevent this needless loss of life. Poignantly highlighted by the bereaved supporter community of SUDEP Action,



emphasised the devastation and crucial need for urgent action.

The aims of the 2018 Prevent21 Summit were to:

1. Highlight learnings on need, gaps and progress in relation to epilepsy deaths
2. Explore key recommendations from panels and summit participants
3. Provide opportunities for multi-stakeholder collaboration to tackle epilepsy deaths

In attendance, we had a wide spectrum of clinicians, policy makers, epilepsy organisations and medical professionals.

Supported politically by MPs from across parties, including Ed Vaizey MP, Norman Lamb MP, Paula Sherriff MP and Ivan Lewis MP.

Ahead of the Summit event, BBC South also featured a report with our CEO, Jane Hanna OBE, on the importance of discussing epilepsy risks and regular health checks.

**Next steps.....**

Our **Summary Report** shows the outcomes and recommendations from the Summit. This report is endorsed by the All Party Parliamentary Group for Epilepsy and the Neurological Alliance.

The findings from the Summit will also be published in a special supplement in the Journal 'Epilepsy and Behaviour', in early 2019.

Further updates on the progress of the outcomes, and videos, will be released in due course.

# SUDEP ACTION URGES MPS AND POLICY MAKERS TO SUPPORT VITAL COLLABORATIVE WORK AND KEY RECOMMENDATIONS TO TACKLE EPILEPSY DEATHS

At the **All Party Parliamentary Group for Epilepsy (APPGE)** at The House of Commons on 28th November 2018, the charity presented the findings and key recommendations from the Prevent21 Summit to MPs, policy-makers, epilepsy organisations and individuals with an interest in epilepsy. The APPGE is chaired by Paula Sherriff MP, who has personal experience of the impact of epilepsy on families.

SUDEP Action gave an expert overview of the key issues about epilepsy deaths, also provided an opportunity for questions and encouraged those in the room to consider how they could help the charity, and supporting organisations, to save future lives:



**Jane Hanna OBE**, CEO of SUDEP Action, then reminded those in the room of why tackling epilepsy deaths is so very important, by sharing a story of one of our bereaved families. She also gave an overview of the UK Prevent21 Summit – the first dedicated event of its kind in the UK since the 1996 workshop on defining SUDEP.

**Professor Mike Kerr**, Professor of Learning Disability Psychiatry, shared the Prevent21 Summit outcomes and recommendations to tackle epilepsy deaths. These **seven key outcomes** were agreed, by all organisations at the event, as being vital steps. Which, if

supported and achieved, could make a significant difference to those living with or supporting those with epilepsy, as well as to those who lose a loved one to the condition.

Key outcomes that are already happening to tackle epilepsy-related deaths were shared at the meeting:

- **Prevent21 Summit Recommendations** are being shared with supportive organisations and policy makers
- **Epilepsy & Behaviour Journal Supplement** will share evidence and outcomes of the Prevent21 Summit. Can MPs and supportive organisations help us circulate this?
- **Letter to Health Select Committee** is being written asking for an inquiry into epilepsy-related deaths
- **A series of Parliamentary Questions** are being tabled by Paula Sherriff MP, Ed Vaizey MP and other supportive MPs EG: Who is the Minister responsible for Epilepsy? Will Neurology / Epilepsy be prioritised in the upcoming NHS 10-year plan?
- **The APPGE and supportive MPs will seek/push for a meeting with Secretary of State for Health and Social Care**, to highlight the Summit recommendations and the need for Government to meet with the bereaved community and support those tackling epilepsy deaths.



- **Epilepsy-related deaths is to become a standing APPGE Agenda item.** With SUDEP Action updating the APPGE on work relating to epilepsy-related deaths at future APPGE meetings – coordinating with other epilepsy organisations, supportive MPs and APPGE Chair in-between meetings to progress actions and achieve outcomes

SUDEP Action will also be working with a core group of supportive MPs in between APPGE meetings to drive forward work in making the Prevent21 Summit recommendations a reality.

The charity have expressed thanks to all the MPs who were able to attend the meeting or were able to send one of their team along; given the incredibly busy times in Government at the moment.



**Dr Paul Morrish**, Consultant Neurologist, presented on the recent Public Health England Report looking at what data into epilepsy deaths show us and government – highlighting the need for Epilepsy to be made more of a priority by Government within the NHS.

## KEY DATES FOR 2019

- Int. Epilepsy Day** (11 Feb)
- Purple Day** (26 March)
- Online Epilepsy Memorial Day** (10 May)
- SUDEP Action National Conference** (17-19 May)
- National Epilepsy Week** (20-26 May)
- SUDEP Action Day** (23 October)

**SUDEP Action**  
Making every epilepsy death count

# SUDEP Action NATIONAL CONFERENCE

## SUDEP ACTION NATIONAL CONFERENCE

### What is the National Conference?

This annual event is a great opportunity to hear all about what SUDEP Action have been working on and how YOUR support has helped. It's also a chance to meet and be with people who understand.

### When is the next Conference?

Dates have been released for the next National Conference – **Friday 17 to Saturday 19 May 2019.**

It will be at the Woodland Grange Hotel, Leamington Spa.

### What will be the topics for this year's Conference?

SUDEP Action will be able to update you on the latest news and research, as well as project and campaign updates. Giving you a chance to ask questions and find ways to further help, input into the charity's activities.

There will also be valuable time for supporters to spend time together, building up new and existing relationships.

The full agenda will be released closer to the date.

### How do I book?

With this newsletter, there is a Conference booking form. Please fill out the form and send it back to the office:

**18 Newbury Street  
Wantage  
Oxfordshire  
OX12 8DA**

Please return your form, with preferred method of payment to **us before booking closes on Friday 12 April 2019 (or before Sunday 31 March to get the 'Early Bird' rate).**

For any queries, please call the office on 01235 772850.

## SUDEP ACTION WELCOMES NEW NEUROLOGICAL PATIENT EXPERIENCE SURVEY

A new neurological patient experience survey is open, to collect vital information about the experiences of treatment and care, social care and welfare received by people affected by neurological conditions such as epilepsy. The survey aims to collect enough data from people living with a neurological condition to positively influence future neurology services.

The survey is by The Neurological Alliance – an organisation that brings together organisations working to make life better for millions of people in England with a neurological condition. Through the patient experience survey, The Neurological Alliance aims to positively influence the future quality of neuro health and social care services. Too often services fall below

the standard expected. This survey aims to help change that.

The Neurological Alliance will publish the results in a report in summer 2019. This report will set out a comprehensive picture of what is happening in relation to neurological services and make recommendations about how care can be improved.

The survey findings will be shared with SUDEP Action and we will use them to add strength to our policy and campaign work – highlighting the urgent need to tackle epilepsy-related deaths by improving information, care and services for those living with epilepsy. This will sit alongside information and experiences already gathered via the Epilepsy Deaths Register from bereaved families, which since its launch in 2013 has highlighted



well known gaps in epilepsy care and lessons which could be learnt to save future lives.

The survey is open from **Tuesday 17th October 2018 to Friday 22 March 2019.** Responses are completely confidential and anonymous. Visit the SUDEP Action website for more information and the weblink.

*"To me, it will be a tangible way of saying a final thank you to an organisation that has helped me continue my life following my saddest of days." – SUDEP Action supporter Roger Scrivens*

### Have you thought about leaving a legacy to SUDEP Action?

Leaving a legacy can help make a difference to the lives of people with epilepsy and those who have lost loved ones. It can help support our research into death prevention, help share our life-saving tools and information and enable SUDEP Action to continue to provide free bereavement support to those who need us.

Your local solicitor will be able to advise you on the different types that are available and how to set one up. Please let us know if you decide to leave a gift.

You can call us on 01235 772850.  
Thank you.

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## DREW

Our Drew. How do I describe our Drew? 22 years old and well, let's say you couldn't miss him all 6ft-odd of him! Our gentle giant. Big ears (he wouldn't mind us saying this as his party piece was sticking them in and making them pop out). Always wore his Monster cap and wrapped up in a big body warmer and shorts, even in the height of summer.

Drew was fantastic artist, he loved Arsenal FC, much to his dad's disgust as we are Newcastle United supporters. He won a 'Give Racism the Red Card' competition, which he got to go to St. James Park, watch a match and meet all the players (his dad, Derek was more impressed and excited to be there than Drew). He loved American football and WWE wrestling, he and his brother, Ray, would roll around the floor when they were little, pretending to be The Rock and Stone Cold Steve Austin.

Drew was a fantastic big brother to his little sister, Grace. She adored him, and so did his big brother Ray and little brother, Matthew, who has autism. Drew was diagnosed with epilepsy at the age of 13yrs and spent nearly two years in a hospital near Stafford, which was devastating for us as he was so far away. Thankfully, he was eventually well enough to return home.

The night of 1st August 2017, Drew headed to bed saying, "tell my dad to get me up". He always got up and even ironed his dad's tops for work and made him a cuppa every morning for work, they enjoyed their chats (or arguing about football).

He said he loved me, as he always did, and asked if he could have some money



for his cigarettes - and those were the last words I'll ever hear him say.

That next morning, I was woken to my husband shouting for me to call an ambulance. We tried, with instructions from the emergency services on the phone, to get him on the floor and start CPR. But looking back I think we both knew he had already been taken from us. The wonderful paramedics arrived and tried to help, but after what felt like forever, we were told there was nothing more they could do. My son, my wonderful boy, my baby was gone.

Our lives will never be the same without our boy. I wake up every morning and for one flash of a moment I've forgotten, then I remember, and the emotions and grief come back.

We are one of the few who had heard of, and knew the risks of, SUDEP. A few years before I had organised a 15-mile charity walk with my darts team, in aid of a charity that was set up by parents

who lost their daughter to SUDEP. But as I have heard and much said, "never thought it would happen to us".

I have set up a Facebook page called 'Being awesome for Drew with Team RH'. Where I will be getting fit, losing

weight and doing all sorts of activities in Drew's memory and raising awareness of SUDEP. I want to celebrate Drew's life and memory. Make him proud, as I was of him, and not let grief swallow me up as grief can do if I let it.

**Sharon (Drew's mother)**

## ALAN

I have (had) two sons, one born 1984, one in 1985. Less than 14 months between them, they were very lively boys, could not breathe in same room without annoying each other. Always used to say I'd hate that time back.

But I so wish I could have it now.

Alan was the oldest. When he was around 25yrs old, he started having seizures. I've seen him resuscitated more than once.

He lost his HGV and car licence. He did get the car one back, twice, but had to be clear for five years before getting HGV one back.

He would say to me he ached some mornings waking up; I would ask him if doctors had said he had epilepsy. His answer always same "Mum I'm ok".

Due to patient confidentiality, the hospital staff could not give me any information.

I believe that Alan was not truthful about having seizures at night, he did not want to lose his licence again, he really wanted his HGV one back.

Alan drove the local dust cart for a job, his granddad (my dad) did as well, he



was very proud. They were like a couple kids together. (Dad passed away in July 2017, so they are back together again) The week before Alan died, he had been sent home being unwell a couple times, it turns out on the Friday he had made a phone appointment with his doctor for the following Tuesday morning.

The doctor rang his mobile on the Tuesday, there was no answer. So, he rang his work, Alan had not arrived.

Two friends went to where he was staying at that time; they found Alan had died in bed.

The previous evening, he had text his friend saying he was scared and that he would have been starting medication after speaking to his doctor.

But it was too late.

Like many others, I found out about sudden unexpected death in epilepsy (SUDEP) on Alan's post mortem result. SUDEP needs to be spoken about by the doctors and consultants and acknowledged. Yes, it may frighten people, but it's too late once a loved one has gone.

Alan would still be here today if I had heard of SUDEP.

We must put pressure onto Parliament to help raise awareness. If we raise awareness, we can lower deaths.

We talk about diabetes and what you need to do to look after yourself. SUDEP should be acknowledged in the same way.

Epilepsy, like any condition, is something you need to make sure that you live as healthily as possible. Look after yourself, rest and sleep when you need to, everything in moderation.

Epilepsy needs to stop being a stigma - you can lead a normal life. People need to be told about SUDEP. Yes, it may scare people living with epilepsy,

but it's much, much, better than dying not realising you could have lived and possibly prevented it.

Alan was also a brilliant golfer, with a handicap of 6, (he once got a hole-in-one aged just 13!). Every year, at the Woodbridge Golf club, they have a memorial game where they have bottles drink in memory on hole 7.

In November 2018, I held an open garden for my 40+20 birthday. Friends and family came along and we were able to collect some donations for SUDEP Action.

On my car I have SUDEP Action signs with photos of Alan on. Not a week goes by, where I don't get someone asking me about them.

Alan is still helping others. One of his sayings was: "I thought about it - it is the thought that counts."

We are the voices raising awareness of SUDEP, helping to save future lives.

Always that empty chair, missing person, broken heart.

**Linda (Alan's mum)**

## THANK YOU



We would like to acknowledge the **Garfield Weston Foundation** and the **Masonic Charitable Foundation** for donating grants to SUDEP Action. We are very grateful for the £20,000 and £4,000 respective contributions. This money will help to further support the work & mission of the charity in preventing epilepsy deaths and supporting bereaved families.

## LONDON 10K

SUDEP Action's Community Services and Fundraising Coordinator **Katie Vale** attended the British Westminster London 10K to cheer and meet a fab team of around 30 SUDEP Action supporters. Katie commented: "I am so proud of all our runners. They did so well to complete the event. The day was incredibly hot which made their accomplishment all the more amazing."



It was great to cheer them on and meet up after the event. Well done everyone!"

## SAMANTHA YEATES

**Samantha Yeates and family** climbed Snowdon in memory of Ray White. Samantha informed us: "My mum lost her older brother, Ray in April this year which was when SUDEP was brought to our attention. Ray had always wanted to climb Snowdon but unfortunately didn't fulfil his dream. On Saturday 7th July, my family and I reached the summit of Snowdon in Ray's memory and spread his ashes so there will always be a part of him there."



We want to raise more awareness for such an amazing charity and to hopefully help others."

## TOM AND XANDER SAMUEL

**Tom and Xander Samuel** ran 21k along the cuckoo trail from Heathfield to Eastbourne on the 2nd August in memory of their Aunty Diane to support the Prevent21 campaign. Supported by Mum, **Michelle** and friends **Jacqui and Noah**. Tom and Xander informed us "It took us 1 hour 53, the middle bit was hard but we were doing it for SUDEP Action, for our aunty who died from SUDEP, so we weren't giving up." Michelle commented "Big thanks to Full Range Fitness for their support at the finish."



## JANETTE DUNION

Janette Dunion and a fab team took part in Rough Runner Scotland in memory of Samantha Dunion. Janette informed us "Samantha, my sorely missed daughter, was only 19 when she was stolen by SUDEP in June 2017. She is very much at the heart of our fundraising challenges. Two more energetic members of 'Sam's Bams' are taking on Man v Mountain in September, the rest of us did Rough Runner (5K meets Total Wipeout and Gladiators). We had somersaults, face plants and some questionable celebration dancing, but we had fun, and Sammie would have loved that."



## KENSA KNUCKEY

Kensa Knuckey ran the Bristol Half Marathon in memory of Joey Sims. "WE DID IT! We completed the Bristol Half Marathon. Shockingly in 2.5 hours - which wouldn't have happened without the amazing Issy Turriff, who sang hymns with completely incorrect lyrics, and a lot of other random stuff. I am very happy it's finally done and the amount you have all helped to raise for an amazing cause is insane, and all in memory of our favourite Joey Sims - thank you to each and every one of you. Sorry for my ugly running face - I have withheld from posting my crying face that featured a few times!"



## DEREK CARTWRIGHT

Derek Cartwright raised money for SUDEP Action by completing a charity swim, in memory of Nathan Slade, who died from SUDEP. He completed 40 lengths of the Riddings swimming



pool in August. A Charity Ball also took place at the Forest Pines Hotel and

Golf Resort, to raise further funds and awareness.

## TONI AND TARYN SLADE

Toni and Taryn Slade organised a fantastic Halloween party in memory of son and brother, Nathan. Toni commented: "Our Halloween Fancy Dress Party for SUDEP Action was chaotic & crazy. Everyone made an effort to dress up & there were some fabulous outfits."



### 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 Officer, [shelly.johnson@sudep.org](mailto:shelly.johnson@sudep.org)

**Awareness and events** - raise awareness by campaigning and volunteering, or attend one of our charity events. [info@sudep.org](mailto:info@sudep.org)

**Fundraise** - You might want to celebrate the life of someone special. [fundraising@sudep.org](mailto: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.**





Please be gentle with me for I am grieving.  
The sea I swim in is a lonely one, and the shore seems miles away.

Waves of despair numb my soul as I struggle through each day.

My heart is heavy with sorrow.  
I want to shout and scream and repeatedly ask, "WHY?"

At times, my grief overwhelms me, and I weep bitterly, so great is my loss.

Please don't turn away or tell me to move on with my life.  
I must embrace my pain before I can begin to heal.

Companion me through my tears and sit with me in loving silence.  
Honor where I am in my journey, not where you think I should be.

Listen patiently to my story.  
I may need to tell it over and over again.  
It's how I begin to grasp the enormity of my loss.

Nurture me through the weeks and months ahead.  
Forgive me when I seem distant and inconsolable.

A small flame still burns within my heart, and shared memories may trigger both laughter and tears.

I need your support and understanding.  
There is no right or wrong way to grieve.  
I must find my own path.

Please, will you walk beside me?  
- Jill B. Englar

To contact the support team call 01235 772852 or  
email [support@sudep.org](mailto:support@sudep.org)

[Sudep.org](http://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:	<a href="mailto:support@sudep.org">support@sudep.org</a>
Getting involved and campaigns:	<a href="mailto:info@sudep.org">info@sudep.org</a>
Fundraising:	<a href="mailto:fundraising@sudep.org">fundraising@sudep.org</a>

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