# Nottinghamshire couple campaigns for better bereavement support after tragic SUDC loss



A couple from Nottinghamshire, Enya Burgess and Scott Stanley, have been left devastated after the sudden and unexplained death of their 14-month-old daughter, Lily-Anne, who was found stiff and blue in her sleep. Despite urgent medical intervention, Lily-Anne was pronounced dead, with no clear cause other than Sudden Unexplained Death in Childhood (SUDC). The heartbreaking event has driven the couple to seek improvements in bereavement support services for families enduring similar tragedies.

Lily-Anne’s passing revealed glaring gaps in the hospital's care for grieving families. After her body was taken to King’s Mill Hospital in Nottinghamshire for further examinations, the couple claim they were left in a busy, chaotic A&E waiting room without a private space to begin processing their loss. They described being moved to a small, dingy room next to the children's A&E area, where the ongoing noise and activity compounded their distress. While some staff, including an A&E nurse and a Chaplain, offered compassionate support by staying late and providing company, the couple say formal counselling and dedicated bereavement services were lacking. They were told that official bereavement support was only available for children below a certain age, which excluded Lily-Anne due to her age.

Enya and Scott have emphasised the urgent need for hospitals to provide private, structured support and counselling for parents immediately following the loss of a child. “Every hospital should have these services on offer for when you lose a child," Scott said. "You need help and support to process the news, and a private place to do so.” The family’s experience has motivated them to launch a GoFundMe campaign aimed at establishing a dedicated bereavement suite and professional support team at King’s Mill Hospital. They hope their efforts will create a lasting legacy for Lily-Anne and ensure other families receive care and compassion in their moment of grief.

Sudden Unexplained Death in Childhood is a rare but profound cause of loss, with around 40 children affected in the UK each year. The SUDC Foundation highlights the scarcity of widespread understanding and research into the condition and offers resources and a community for affected families. Similarly, institutions such as Cincinnati Children's Hospital provide comprehensive information on SUDC and materials to assist families coping with their grief, underscoring the need for better awareness and support. This need for robust bereavement services is echoed by numerous NHS trusts across the UK, which offer practical and emotional support but often rely on signposting families to external organisations rather than providing ongoing counselling onsite.

Hospitals like King’s College and St George’s University Hospitals have dedicated bereavement teams that assist families with the process after a death occurs, offering guidance through legal and administrative steps. However, ongoing emotional support can vary significantly between institutions, with many encouraging families to seek help from charities such as The Compassionate Friends UK and Winston’s Wish. These organisations provide peer support, helplines, therapeutic interventions, and community connections to help bereaved families navigate their complex grief journeys.

Sherwood Forest Hospitals Trust, under which King’s Mill Hospital operates, has expressed condolences to the family and acknowledged the importance of improving their bereavement services. The Trust stated it is committed to enhancing support and working closely with families like Enya and Scott’s to develop lasting improvements. This collaboration aims to ensure that families facing sudden child loss have access to comprehensive and compassionate care.

The tragic experience faced by Enya and Scott highlights the urgent need for hospitals to not only treat the physical aspects of a sudden death but also prioritise the emotional well-being of grieving families. As they continue to campaign for change, their hope is to transform the care environment for others during some of life’s darkest moments, turning their personal loss into a force for positive change.

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* Paragraph 1 – [[1]](https://www.the-independent.com/life-style/health-and-families/sudc-meaning-awareness-nottinghamshire-b2784667.html)
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* Paragraph 4 – [[2]](https://www.sudc.org/), [[3]](https://www.cincinnatichildrens.org/health/s/sudc)
* Paragraph 5 – [[4]](https://www.kch.nhs.uk/services/services-a-to-z/bereavement-support/), [[5]](https://www.stgeorges.nhs.uk/patients-and-visitors/help/bereavement-services/), [[6]](https://www.tcf.org.uk/), [[7]](https://www.winstonswish.org/)
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## Bibliography

1. <https://www.the-independent.com/life-style/health-and-families/sudc-meaning-awareness-nottinghamshire-b2784667.html> - Please view link - unable to able to access data
2. <https://www.sudc.org/> - The SUDC Foundation is dedicated to raising awareness, funding research, and supporting families affected by Sudden Unexplained Death in Childhood (SUDC). They provide resources, information, and a community for those impacted by this rare condition, aiming to uncover its causes and offer support to grieving families.
3. <https://www.cincinnatichildrens.org/health/s/sudc> - Cincinnati Children's Hospital offers comprehensive information on Sudden Unexplained Death in Childhood (SUDC), detailing its definition, potential causes, and the challenges in identifying risk factors. They also provide grief support resources for families coping with the loss of a child due to SUDC.
4. <https://www.kch.nhs.uk/services/services-a-to-z/bereavement-support/> - King's College Hospital NHS Foundation Trust provides practical and emotional support to families and those close to patients who have died in their hospitals. Their Bereavement Support team guides individuals through necessary steps following a bereavement and offers assistance with related procedures.
5. <https://www.stgeorges.nhs.uk/patients-and-visitors/help/bereavement-services/> - St George's University Hospitals NHS Foundation Trust offers Bereavement Services to guide individuals through the necessary steps following a bereavement. They provide support and assistance with procedures related to the loss of a loved one.
6. <https://www.tcf.org.uk/> - The Compassionate Friends UK is a peer support group formed by and for parents whose children have died. They offer a national helpline, local and national meetings, and various resources to support bereaved parents and their families.
7. <https://www.winstonswish.org/> - Winston's Wish is a UK-based childhood bereavement charity that provides practical support and guidance to bereaved children, their families, and professionals. They offer therapeutic help in individual, group, and residential settings, as well as a national helpline and interactive website.