

Newsletter Spring/Summer 2025

Nursing care at home for local children with life threatening or terminal illnesses and support



Meet Jude! Since birth, he has received vital support from The Sussex Snowdrop Trust, including specialist nursing care at home and assistance with transport costs for hospital visits. Now a pupil at Fordwater School in Chichester, he continues to benefit from an additional trustfunded nurse who provides essential care for him and other children with complex medical needs.



Jude was born in July 2016, arriving six weeks early but weighing a healthy 7lb 4oz. Just four days later, his life changed forever. His mum, Amee, recalls:

"Jude caught a common cold, which led to encephalitis and sepsis. He was fighting for his life, but Jude beat the odds. Life was uncertain, but he showed tremendous strength—traits he still carries today."

Then diagnosed with epilepsy, Jude faced further hospital visits due to chest infections and seizures. Having a PEG fitted significantly improved his quality of life, and Jude enjoyed a whole year out of hospital. However, new challenges soon emerged with a diagnosis of dystonia and subsequent billateral hip surgery. Jude's scoliosis had also progressed rapidly and at just five years of age, he underwent surgery to have titanium rods inserted. Unfortunately, in the summer of 2023, he was to experience serious complications and a gruelling three month recovery. Jude's journey has been filled with unimaginable challenges, yet his strength and courage continue to shine. He truly is a superhero!

Jude's Strength and Smiles

Despite everything he has faced, Jude continues to smile every day. His resilience, combined with the unwavering support of The Sussex Snowdrop Trust, has helped the family throughout.

Through sheer determination, Jude healed and made his way back to school. While his scoliosis journey is ongoing and long-term pain remains a challenge, his love for movement and stimulation fuels his determination. His family is committed to ensuring he thrives and lives as comfortably as possible. Thanks to the Snowdrop funded nurse at Fordwater School, he receives vital support that makes a real difference.

Like so many Snowdrop children, Jude's resilience in the face of illness is truly inspiring. It's always a joy to see him and his family at Snowdrop events—whether he's ice skating in his wheelchair, celebrating at the Christmas party, or visiting the farm to see newborn lambs.

Bringing Joy to Snowdrop Families

The Sussex Snowdrop Trust is incredibly grateful for the wonderful community collaborations that help bring joy to our families, creating special moments together.

One of the highlights of the year is our Christmas Party, a much-loved tradition where over 40 Snowdrop families gather at Butlin's in Bognor Regis for a day of festive fun. This magical event is made possible thanks to the generosity of our supporters. This year, gifts were kindly donated by Dunelm Chichester, V2 Radio listeners, Mission Christmas Appeal supporters, and the wonderful team at Medip. Santa's gifts were provided by Mamaloveshighstreet, ensuring every child received a chocolate treat!

This party is a cherished time for families, allowing siblings and grandparents to relax and enjoy some much-needed fun together. The Care at Home Team also attends, and it's heartwarming to witness the unique and special relationships between our Snowdrop families and these dedicated professionals. (Pictured: the igloo, supplied by Pitch Up and Co.)

Another exciting experience is ice skating at the Bognor Ice Rink, run by the Coles family. This activity appeals to some of our Snowdrop teenagers who also like the waltzers and dodgems—a fantastic opportunity for fun and adventure!

Moments like these remind us how important it is for families to share joyful experiences together, and we are so grateful to everyone who helps make them possible.





A Special Day on the Farm

There's nothing guite like seeing the excitement of our Snowdrop children as they gather to watch a baby lamb being born, gently hold a tiny newborn chick, or enjoy a bumpy ride in a tractor trailer!

We are incredibly grateful to the owners of Lurgashall Farm for hosting such a memorable day, complete with a delightful homemade afternoon tea at their farmhouse. The children also explore the farm on a fabulous egg hunt and leave with chocolate eggs kindly donated by Nuffield Health Centre in Chichester—a perfect end to a magical day!

Family Day Out

Caring for a seriously ill child can be overwhelming, often leaving little time for the simple joys of family life or a holiday away. That's why, every summer, our charity gives Snowdrop families the opportunity to enjoy a memorable day out. Families can choose from exciting options like Legoland, Paultons Park, or Fishers Farm - with older children often opting for a cinema trip. We also provide a £50 Tesco voucher to help cover travel expenses.

The feedback we receive from families is wonderful. These days out provide an invaluable chance for families to spend quality time together, creating cherished memories that many wouldn't otherwise have the opportunity to experience due to financial constraints. It's a truly special gift that brings so much joy to our Snowdrop families.





Supercar Day at Goodwood

For many children—and even adults—getting up close to extraordinary supercars is a dream come true! The Saywell International Supercar Track Day at the iconic Goodwood Motor Circuit provides just that, offering an unforgettable experience for Snowdrop families, as well as hundreds of car enthusiasts from around the UK.

Thanks to the incredible generosity of Peter Saywell, Managing Director of Saywell International, this event is completely free for all attendees. Some of our Snowdrop children even have the thrill of being passengers for a special 'slower' lap around the track—an experience they will never forget! Next Track Day - Saturday 28th June!

Thank

Community Heroes

you!



Shaun Drew 5K Update

Shaun, uncle to Snowdrop child Tallulah, showed real dedication as he ran 5k every day, for a year in 2024! He completed 366km and raised over £5000k with Prydis Legal, his employer, adding an additional £900 through other social fundraising initiatives. This is a truly outstanding challenge!



Help us, help children like Jude... no family can do this alone

The anxiety of not knowing what the future holds for your child's health and the overwhelming amount of new information to navigate can be crippling. Going forward, the life of a Snowdrop family will never be the same and the impact of the illness stays with the family forever. It invades time spent with siblings, impacts a family's social life and can have an effect on their income too.

For families facing the unimaginable reality of caring for a child with a life-threatening or terminal illness, every moment together is precious. The Care at Home team provides essential nursing care and comfort, ensuring families are supported in the familiar, loving environment of home whenever possible. But this vital service depends on the generosity of donors like you.

How can you help? The Power of Regular Giving

When you become a regular donor, you join a special group of people. Your monthly contributions help fund essential professional nursing care, emotional support through our counsellors, and respite for exhausted parents.

Why Regular Giving Makes a Difference

Regular giving provides consistent, dependable funding - giving the trust greater longevity and the ability to plan ahead.

As a regular donor, you will receive updates on how your support is making a difference through our newsletter, along with stories from the families you are helping. Every donation helps us - please help us to help our Snowdrop families.



Our way of saying thanks!

Make a lasting impact today, and as a thank you for you signing up as a monthly donor, we will send you a Snowdrop mug - spread the word over a cuppa and tell your friends how your donation is making a difference to the lives of young people.

Sign up on our website, call us or set up a standing order with online banking to give a monthly or a one off donation. However you choose to give, it will help us enormously.....

Set up a standing order

The Sussex Snowdrop Trust

Sort code – 30-91-97 Account number – 02271507



Sky drop for Snowdrop

The Duchess of Norfolk and her friends, Linda Woodhouse and Katherine Bergen Coughlin, are taking to the skies to 'Sky drop for Snowdrop'

Our new Patron, Chica Norfolk is literally throwing herself out of a plane in a tandem skydive of 10,000ft!

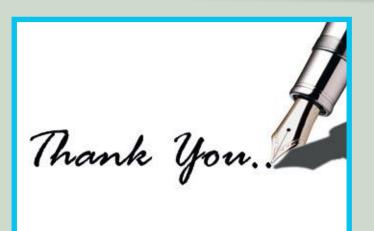
Di Levantine, our Co-Founder, expresses profound admiration for the Duchess's unwavering dedication to Snowdrop. She commends her heartfelt interactions with volunteers, nurses, and parents as well as her presence at events such as our coffee morning and AGM. Her emotional experience with Snowdrop children at Fordwater school further demonstrated her commitment. Di is in awe of the Duchess's bold decision to undertake a skydive, calling it an inspiring and courageous way to show her support. We hope many will sponsor her as she takes to the sky.



To Donate

www.justgiving.com/page/the-sussex-snowdrop-trust-8 or go to our website.

Tell them that Snowdrop is our lifeline!



Snowdrop were there from the start - they are amazing, helping with nurses coming into the home, transport and financial support. They are just a really good charity for the local area which we are lucky to have. Snowdrop recognises that siblings need support as well. They also provide a counsellor who works with the families and understands what we are going through.

- "You have helped us in so many ways over the past eight years since our daughter was found to have a serious illness. We don't know how we would have coped without the wonderful care provided by the nurses and your financial support "
- "We simply cannot put into words our thanks and gratitude to you all. The kindness and dedication you showed us, we will all remember forever. Our daughter is in our thoughts every second, she was the most wonderful girl and we were so lucky to have her. Most evenings we discuss how terrible it could have been, her last days and her peace of mind. Without Snowdrop we would never have been able to achieve a peaceful death at home. When the hospital visits were over and she was home for good, she was somewhere she loved to be without you we could not have done that. Thank you seems inadequate, but it is all we can say."

Upcoming Events -Full details on our website.



Sunday May 11th - Annual Walk - Arundel Castle Estate Park, BN18 9AU - Walk between 1 and 3pm

Walk 1 or 5 miles. Adults $\mathfrak{L}5$, Child $\mathfrak{L}3$, Under 3 FREE – Pre register or sign up on the day. Dogs on leads are welcome and sponsorship is encouraged for dogs and walkers of any age. A fun filled day for all!

Tea tent, ice cream, raffles and games - FREE parking.



Friday June 13th – Local Farmer, Ryan Haydon 'In conversation' with James Stewart from the Zimmer Stewart Gallery and local artists.

South Stoke Barn, BN18 9PF

6.30pm - Champagne & canapes reception - £25 ticket



Sunday May 25th - T10 Villages Cricket Match at Arundel Castle Cricket Club - BN18 9BA, Gates open 9.30am - Play starts at 10.30am

FREE entry - event sponsored by Monan Gozzett LLP.

Teams from Aldwick, Fernhurst, Arundel Grasshoppers and Madehurst. Live music, pizza, ice cream, cream teas, raffle and outdoor vintage games.



"Treasures from your Home" - An evening with Rupert Toovey!

Tickets available from August www.thebct.org.uk

Friday 3rd October - Champs Hill, near Pulborough, RH20 1LY



Diana Levantine

Chairman & Co-Founder

Dr Marco Cavaroli

Vice Chairman & Trustee

Trustees

Caroline Bechelet-Carter

Nick Cockram

Tony Jago

Valerie Seddon

James Tickell

Kathryn Flanagan

Patrons

Mary Bowerman

Tommy Boyd

The Rt Hon. Lord Herbert

of South Downs CBE

Rt Rev. Bishop Richard Moth

(Bishop of Arundel & Brighton)

Duchess of Norfolk, Chica Norfolk

Hugh Dennis

Dame Patricia Routledge DBE

Rt Rev. Dr Martin Warner (Bishop of Chichester)

Snowdrop and Children's Community Team

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People's Postcode Lottery

Just before Christmas, the charity received what Di Levantine, Co-Founder and Chairman, called "the best Christmas present ever!", while being filmed by representatives from the People's Postcode Lottery Community Fund. Staff from the Care at Home Team, Trustees, and office staff gathered at the Walberton office for the exciting reveal—an incredible £90,000 donation. The Trust was overwhelmed by the news, especially as they must raise £500,000 annually to fund the Care at Home Team. This generous contribution provided a significant and much-needed boost to the charity's fundraising efforts. Despite this large donation, we need your ongoing support more than ever - every donation contributes to the support so desperately needed for local children who have been diagnosed with a life threatening illness.



Make a Donation (

You can make a donation by:

- Filling in the donation form below and returning to us by post to the Walberton Office.
- Visiting our website: www.thesussexsnowdroptrust.com and click on the green heart to donate.
- Setting up a standing order with your bank: Sort code - 30-91-97 Account number - 02271507
- Leave The Sussex Snowdrop Trust a legacy in your will - talk to your solicitor about how to do this.



Please call the Snowdrop office on 01243 572433 to make a donation by debit or credit card.

Text the word SNOWDROP to 70085 followed by the amount you'd like to donate for example: Snowdrop 10 to donate £10 Snowdrop 20 to donate £20 etc



N.B. Your usual standard rate message charge will apply

Donation Form	Date
I/We would like to make a donation	and enclose £
Title First Name	
Surname	
Address	
	Postcodo

PLEASE TICK IF ELIGIBLE. Please treat this donation as Gift Aid. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my Gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

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Please make your cheque payable to The Sussex Snowdrop Trust and send your donations to: The Sussex Snowdrop Trust, Unit 3 The William Booker Yard, Walberton, West Sussex BN18 0PF.