



Newsletter

Spring/
Summer
2026

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



Each year, incredible individuals take on physical challenges to help raise vital funds for the Trust. We have a small number of places for the London Marathon and we are delighted to share the motivation and purpose behind two of our runners....

Kayleigh is a Snowdrop Mum and needed the support of the Care at Home Team over 13 years ago. We recognise that the help a family receives at the most traumatic time in their lives is never forgotten....

She announces; "I have decided to run the London Marathon in April to raise money for this incredible charity that went above and beyond to support me and my family!

Now it's my time to give something back to them. I want them to be able to continue to provide all the amazing care and support that I received to other families who need them. I could

not have got to where I am today without the support from my parents and the Snowdrop Trust!

Kayleigh bravely shares her story of how Snowdrop has supported her when one of her twins became terminally ill.

'I gave birth to identical twins, Taylor and Jordan at 34 weeks. As a mum of 22 years old, life was exciting caring for my two boys. However, things began to change when Taylor started vomiting regularly from aged 6 months old. The hospital thought he had a lactose intolerance so I sought an alternative formula. Then other signs of development began to emerge. Jordan sat up, while Taylor would fall sideways. Then Jordan began to walk but Taylor was unsteady on his feet.

When the twins were 14 months old, there was more hospital visits and finally a CT scan revealed a diagnosis of hydrocephalus.

Stay up-to-date with stories and fundraising

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We were assured that he would make a full recovery but just a few days after the operation our family received the devastating news that it was in fact a brain tumour! Our worst nightmare.

We were given a LOT of information very quickly and the next day Taylor was in theatre having the tumour removed. My 14 month old baby was having brain surgery, this was terrifying! We were told there was a possibility he could die during surgery which was absolutely gut wrenching! As a family we sat in a room for 8 hours, desperately hoping the surgery was successful and that we would see Taylor again.

We were then referred to the Care at Home Team at Snowdrop. I thought they were just about nursing support team, but they provided so much support for me. I was a single mum of twins. I don't think people appreciate how expensive it is to stay in hospital for long periods of time with your child. I had to buy food for myself every day and there was also the petrol and parking costs, plus clothing for Taylor to make sure he was comfortable, whilst still running a home and providing for his twin brother Jordan. At this time, The Snowdrop Trust became our support. They hired a car for me for several months, until I could get my car fixed, so that I could drive to Southampton for daily radiotherapy, and frequent chemotherapy treatments. I was honestly so grateful!



“ Alongside financial support, nurses came to our home and provided nursing care. They would organise Taylor's medication, dressing changes, provide equipment etc. Every nurse was so friendly and supported us in every way we needed. They never left Jordan out. He didn't need nursing care but they always made sure they engaged with him and made him feel included at every visit. ”

We were also given days out as a family. This is invaluable to me and Jordan now, as we were very lucky to have made some amazing memories with Taylor, that we will cherish forever! We visited Peppa Pig World multiple times, attended Christmas parties, and requested equipment to make life easier!

It was not only a stressful time for me and Taylor but also for Jordan. He had to live with my parents for an extended period. Snowdrop's counsellor, Phil would visit us at home and play games with the twins. I will never forget 'duck, duck, goose'. This was a favourite of the twins. He also gave us all emotional support throughout our whole journey. This kind of support meant the world to us. I know Jordan will be forever grateful!

Taylor was the longest living child in the world with this type of cancer! What a fighter!! We were put in touch with a doctor at

“ The Snowdrop Trust supported me through every decision I made, with no judgement! They continued to support us at home during this course of chemo. This felt like a good option as it meant Taylor could be at home with his family and not in hospital as we had spent most of his life in and out of hospital. ”

the Royal Marsden who wanted to start a clinical trial on Taylor. After lots of thinking and discussion with my family I decided not to go ahead. The trial hadn't even been tried on rats and I didn't feel it was fair to put my young son through this. We went away with some oral chemotherapy to try and prolong his life.

Sadly in 2013 signs that cancer was growing began to show. The Snowdrop Trust supported us at home with a feeding tube, medication, dressing changes, personal care and so much more. As well as continuing with the Tesco vouchers weekly, to ease financial pressures, as I was still unable to work.

Taylor was a home boy and loved being around his family. So we decided as a family that we would keep him at home when he passed. This meant daily visits from the nurses to change the medication in his syringe driver and huge emotional support. They were on call for us 24/7 towards the end. I know I phoned them multiple times day and night and they attended very quickly every time. I had never experienced the end of life before so I felt as though I didn't know what I was doing, but they were there every step of the way right up until the day Taylor passed away, which was 14/7/2013 aged 5 years old.

We received emotional support from Phil, the counsellor at that time.

This year it has been 13 years since Taylor passed away. Time really does fly!

Since then I have had another child and trained to be a midwife. I'm now at a place in my life where I finally feel stable. The pain of losing a child never goes, but it definitely does get easier with time. Or you learn to live with it, one or the other.

Jordan still struggles in many ways. We were told that losing a twin is like losing a limb. I have no idea how this must feel for him, and he is not great at saying how he feels.

But I am so proud of who he is today. He has been through so much but he is the most caring, polite young man I have ever come across. His birthday is always a bitter sweet day, celebrating him and celebrating Taylor. This year he turns 18 and I'm super excited to see where his life will take him.”



Running with Purpose - Eddie

Another London Marathon runner this year, is Eddie Scott, the grandson of Di Levantine, Chair and Co- Founder of the Trust. He is passionate about raising funds for the Trust...

Eddie explains, "Last year, while working with a landscape gardener, we got chatting about family life. He mentioned that he was taking his family to Legoland Windsor Resort and told me that an amazing charity had paid for the trip.

"That charity was Snowdrop," he said.

I was so proud to tell him that my grandmother co-founded Snowdrop 32 years ago and that she still works for the charity every single day. I've grown up with Snowdrop being part of my life — it's always been there in the background, helping families who need it most.

He went on to explain that his little son requires a great deal of care and has been in and out of hospital for operations. Throughout it all, Snowdrop nurses have supported them constantly. They've been there during the hardest times, providing expert care and reassurance when the family needed it most.

As a father, he is nothing short of incredible. I think the world of him. He works tirelessly to provide for his family, balancing the pressures of work with the hospital visits and the emotional strain of having a seriously ill child. Hearing firsthand how much Snowdrop meant to them really brought home the difference the charity makes.

Not long after that conversation, I heard there was a Marathon Place available to raise money for Snowdrop. As someone who runs in my spare time, I jumped at the chance. It felt like the perfect way to give something back to a charity that has been such a big part of my life — and that continues to change the lives of families like his.



I'm now training hard and hoping to raise as much money as possible. Every mile I run will be for the children and families Snowdrop supports — and for the nurses and counsellors who are there through it all.

If you'd like to support me, I would be so grateful. Together, we can help Snowdrop continue its incredible work for many more years to come."

We wish all our runners the very best, we know how committed they are to their training and fundraising – London Marathon Runners – Kayleigh Hurst, Eddie Scott, Sam Morton, Ranald Lloyd-Williams, Alison Finniear.

Brighton Marathon runners – Dominic Buckle, Ethan Samuels
Brighton 10k – Eran Frith, Patrick Ford, James Norman.

Head to our website, www.thesussexsnowdroptrust.com to donate, stating the runner you wish to support.

We will share their medal photos in our next newsletter!

Great News!

We are delighted to welcome Jess Breach as a new Patron. Jess has been linked to the charity for a number of years whilst she built her rugby career in West Sussex. She is now a professional rugby union player for Saracens and England. She delivered a record breaking debut in 2017 and has achieved more than 50 caps. She was the top try scorer for England when they won the 2025 World Cup.

She has been granted the Freedom of the City in Chichester 2026 and is one of England's most outstanding rugby talents and is passionate to give back to her community.



20 years of Phil, a Snowdrop Counsellor

By Di Levantine - Chairman & Co Founder



Phil Portway joined Snowdrop and the Care at Home Team 20 years ago. At the time, he was the last candidate to be interviewed and not the early front-runner. But from the moment he spoke, everything changed. His interview left a lasting impression, and little did the panel know just how much of a difference Phil would go on to make, not only to the Team and Snowdrop families, but to everyone at 'Snowdrop'. Thank you 'Snowdrop Phil' from all of us who have known you for 20 years and everybody who has worked with you during that time.

Phil, shares his story of being a Counsellor.....

“Being a Snowdrop counsellor is like being a guide through Hampton Court maze. Families enter the maze not knowing which way to turn and I am able to say, ‘I will walk with you and show you the path to take’.

”

My work entails being alongside families, accompanying them on their children's journey through traumatic illness and sometimes bereavement. We will work with the sick child, their parents, siblings and sometimes grandparents. All of which have their own needs and emotional journeys. There are often times a seriously unwell child will bring to the fore previous experiences and traumas for those around them.

Bereavement work is an important part of the counsellor role, helping families know that they will be okay after the loss of a child.

My colleague Julie and I use EMDR (Eye Movement Desensitisation and Reprocessing), a therapy that helps people work through upsetting or traumatic experiences. Using gentle techniques like guided eye movements, EMDR can make difficult memories feel less overwhelming and help reduce anxiety, guilt, and process feelings of grief. It allows people to know they did their best in an impossible situation.

We also use sand tray therapy, which allows children (and adults) to express their feelings without words. Using a tray of sand and small figures or objects, they create scenes that reflect their thoughts and emotions. This helps them safely share difficult feelings, work through trauma or grief, and begin to heal through creative play. Memory jars also continue to be a meaningful part of our work with grieving families, helping families to treasure the positive memories and good times spent with their child.

Julie and I also provide emotional support for each other and the nursing team to enable us all to give our very best to each child's family along the Snowdrop pathway.

The annual Snowdrop Walk at Arundel Castle Estate Park is always a highlight for both patients and counsellors. It allows us the chance to meet families we have known for years, as well as those we are currently supporting. Every year I walk alongside a bereaved dad who I first walked alongside as a counsellor in 2007, and it is a privilege to catch up with him and all the other families there.

I am often asked how I do this work. I do it is because the families, Julie, the nursing team and Snowdrop give as much to me as I do to them.”



Many Snowdrop families have recognised the vital impact of Phil's work over the years. One mum who was supported from her child's diagnosis and sadly through bereavement explains how important it was to have his support.

“ Kate comments; “ As Rupert's mum, the loss and pain I experienced has, at times, crippled me. The dark clouds of grief are horrendous, and debilitating. I feel I owe my life to the counsellor. I can honestly say I don't know where I would be without him. I know that no one wants to imagine themselves in our position, but, if the worst ever happens, we are so lucky to have such an incredible charity locally. To pick you up, care for the whole family, and to hold your hands through the darkest days.”

The Sussex Snowdrop Trust is truly unique. While there are other Care at Home Teams that exist, none that we know of, have counsellors as an integral part of their team, making the support Phil and Julie offer to families and staff alike, truly special.

The Trustees of the Board presented Phil with a 20 year service trophy.

Snowdrop Support Workers in Action

Snowdrop Support Workers, who are also part of the Care at Home Team, recently spent two special days with families at the Goodwood Activity Centre for a “Snowdrop Day in the Woods.” Together with staff from the Goodwood Education Trust, they hosted a fun-filled programme of forest adventures and a visit to the farm, creating a memorable experience for everyone involved.

Families were able to play, explore and take part in a wide range of nature-based and bushcraft activities. These included den building, natural crafts, woodland jewellery making, leaf printing, wand making, marshmallow toasting and creating bird feeders. The mud kitchen proved to be a huge hit with the children, while the hammocks quickly became another firm favourite.

Each day ended with a visit to the farm, where families were delighted to meet the newly born calves.

Days like these are just one part of the support provided by the Snowdrop team. Support workers regularly organise activities for children, young people and their families both in the community and at home. These include visits to sensory rooms, local toddler drop-in sessions and days out to places



such as the Aldingbourne Country Centre, Fishers Farm and The Range.

In addition, Snowdrop support workers sometimes accompany nurses on home visits, providing distraction and support for children while nursing tasks are carried out. Their work helps families feel supported, connected and able to enjoy meaningful experiences together.

Connections Count!

The connections we build within our community are invaluable. Every time a community group, individual or business chooses to support us, they help raise vital funds and introduce our charity to a new audience – widening understanding of the work we do and the families we support.



Celebrating 25 Years with F & P Interiors

One inspiring example is F & P Interiors, who marked their 25th year in business with a pledge to raise £3,100 – enough to cover a month's worth of petrol vouchers for families struggling to afford trips to hospital for treatment.

Through fabric remnant sales and an impressive cycle challenge, the team not only reached their target but exceeded it. Their commitment will make a direct and meaningful difference to local families.



Ongoing Support from Highdown Garden Centre

For the past five years, Highdown Garden Centre near Ferring has provided a fantastic venue for selling our merchandise. Thanks to sales and generous customer donations, we have raised significant funds to support our services – just over £10k to date.

Having a permanent space within the centre allows us to showcase upcoming events and share our latest newsletters, helping to keep visitors connected with our work.



A Mountain-Sized Challenge from The Stephenson Group

This year, The Stephenson Group took on an extraordinary challenge, raising an incredible £10,000 for our charity.

Eleven team members completed a demanding seven-day trek across the Gran Paradiso, reaching altitudes of 3,152 metres. Along the way, they were rewarded with breathtaking views of Mont Blanc, Monte Rosa and the Matterhorn. In preparation, they tackled training hikes up Ben Nevis and Helvellyn.

We were honoured to be one of three charities selected through nominations to share in £36,000 raised with the support of their suppliers, subcontractors and hundreds of workers on site.

Gifts that keep on Giving

This year's Winter Market at Grittenham Barn was our most successful yet!

Set in a stunning Sussex Barn, the event welcomed wonderful supporters who came along to soak up the festive atmosphere and shop for gifts for their loved ones.



Thanks to everyone who attended and supported the stalls, we raised an incredible £7,322.10 – a record-breaking total that will go directly towards supporting local families.

If you have an opportunity to nominate us as your chosen charity, are considering taking on a fundraising challenge, or would like to host an event, we would love to hear from you. Please get in touch at office@snowdroptrust.com and help us continue to build connections that truly count.

Events

Sunday 10th May – Annual Walk at Arundel Castle Estate Park – BN18 9AU

This much-loved annual walk takes place with the kind permission of the Duke of Norfolk.

Whether you fancy a gentle 1km stroll or a more energetic 5km route, there's something for everyone. Enjoy a wonderful community atmosphere, complete with homemade cakes, ice creams, raffle, tombola and fun children's activities — including a tractor trailer ride this year, generously provided by the Norfolk Estate.

Adults -£7.50, Children £3, Under 5 are Free, Dogs -£3

Everyone who takes part receives a medal and every dog is given a charity bandana.

Book tickets online for faster registration or pay on the day.



Sunday 5th July – T10 Villages Cricket – Arundel Castle Cricket Club

FREE entry – Thanks to sponsorship from Monan Gozzett LLP Solicitors. Watch village Aldwick, Arundel Grasshoppers, Fernhurst and Madehurst play.

A quintessential pastime at this most beautiful ground with refreshments available, live music, raffle and cricket!



Sunday 21st June – Walberton Open Gardens – 1-5pm

Snowdrop volunteers will be serving cream teas at Walberton Village Hall, which is being sponsored this year by Payne & Ford, Garden and Grounds specialists.



Festive Giving at the Christmas Hoedown

This year's Christmas Hoedown at Butlin's was a truly magical celebration, with 126 children enjoying an afternoon filled with fun, laughter and festive cheer. Each child received a sparkling cowboy hat, met Father Christmas, and tucked into a delicious chocolate treat – generously sponsored by Nature's Way Foods Ltd.

Thanks to the wonderful donations from V2 Radio, Medip, Dunelm in Chichester and Crossfit Tigerlily, children were able to choose a special present to take home, making the day even more memorable. Families also had the opportunity to capture the moment with a photograph to treasure, kindly supported by GWCA Solicitors.



Events like these are so important. They create precious opportunities for families to spend quality time together – siblings, grandparents and loved ones all sharing in the celebration – alongside our dedicated Care at Home Team, who were delighted to be part of the festivities.

Who we are...

Diana Levantine
Chairman & Co-Founder

Dr Marco Cavaroli
Vice Chairman & Trustee

Trustees
Caroline Bechelet-Carter
James Tickell
Kathryn Flanagan
Nick Cockram
Tony Jago
Valerie Seddon

Patrons
Mary Bowerman
Tommy Boyd
The Rt Hon. Lord Herbert
of South Downs CBE
Duchess of Norfolk, Chica Norfolk
Hugh Dennis
Jess Breach
Rt Rev. Dr Martin Warner (Bishop of Chichester)

Snowdrop and Children's Community Team
The Westhampnett Centre
28-29 Westhampnett Road
Chichester, West Sussex
PO19 7HH

Registered Charity and Office Address
Unit 3, The William Booker Yard, The Street,
Walberton, West Sussex BN18 0PF
T: 01243 572433
E: office@snowdroptrust.com
W: thesussexsnowdroptrust.com

Walberton Office Team
Lucy Ashworth
Fundraising, Events & Media Manager
Ellie Hanks Finance Manager
Louise Peddle Office Administrator

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How Can You Help?

There are so many simple — but powerful — ways you can support our work.

We collaborate with local organisations to host a variety of events throughout the year, and we would love you to join us. If you can't attend, sharing event details with your friends, colleagues or community groups, makes a real difference too.

To be the first to hear about upcoming events, raffles and news, subscribe to our mailing list via our website or call us on 01243 572433.

Enter Our Online Raffles

We regularly run online raffles featuring prizes generously donated by fantastic local businesses. By taking part, you're not only in with a chance of winning something special — you're also directly supporting local families.

Spread the Word

Following us on social media, and liking and sharing our posts, helps raise awareness across the community. Every share increases our visibility and helps more people learn about the support we provide.

However you choose to get involved, thank you — your support truly makes a difference.

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.

THE SUSSEX
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TRUST



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

Postcode

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.

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