

Meet Community Nurse, Nikki

Nikki joined the Community Team three years ago and has never looked back. Here, she tells you what community care means for the children, young people and families we care for and how your kind support makes a difference.

What were you doing before you started working in children's hospice care?

Before I came to Leo House, I was an adult nurse working on an acute admissions unit at a very busy local hospital. While I did enjoy it there, I often felt rushed and unable to deliver the level of care that I would have liked. But at Leo House I have a lot more time to get to know the children and their families and I go home every day feeling like I've done a really good job. It's the most rewarding thing I've ever done in my professional life.

Who do you provide care for?

I have a caseload of 28 children and young adults that I visit in their homes across Sussex. They can be anything from a premature baby with a condition that means their life is going to be short, right through to a teenager who has a condition that will end their life before they reach adulthood. As a nurse I'm there to look after all their clinical needs such as medication, feeding, and managing their pain, but also to help them have as much fun as possible!

What does a typical visit look like for you?

When I visit a family's home, each child and family is empowered to make a choice about what they want to do. There isn't really a 'typical' visit as it will always depend on the individual child or young person's needs. They might want to go to the cinema, visit the beach, hang out at home, or even watch a sibling's school performance. Whatever they want to do, we always try to make it happen.

How are parents and carers supported?

As well as providing care and activities for children, community visits also give parents and carers some respite and an opportunity to take time away from their round-the-clock caring duties. Sometimes I visit in an evening so parents and carers can go out for dinner, or they might use the time to get on top of housework, or simply catch up on a few hours' sleep. Whatever happens, I'm there to take care of their child's care needs, allowing kids to be kids and mums and dads to be just that.

What is the most rewarding part of your role?

Getting to know families and helping them create lasting memories is a privilege and this is particularly important when a child is nearing the end of their life. We're there to help families say goodbye in whatever way

feels right to them. And at this difficult time, I'm often involved in complex decision making and symptom management to make sure their child is as comfortable as possible. We also offer bereavement support to help families for as long as they need in the way of counselling, bereavement groups, and play therapy for siblings.

Do you have a favourite memory from the last year?

Recently we put hours of careful planning into making a dream come true for a 10-year-old boy who wanted to climb the nets at an adventure playground for the first time. He's on long term ventilation and can't breathe without his tracheostomy so needed three of the community team on hand to make this trip out happen. Two of us stayed at the bottom of a slide (the quickest route down!) with all the equipment he'd need if he got into any trouble, or his tracheostomy came out. He had the most amazing time.

Contact us

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If you'd like to make a donation directly into our bank:

Sort code: 40-14-01
Account no: 51335979
Name: Leo House

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Brighton and Hove Mayor's Charities

We were excited in early 2020 when we received the letter telling us that Councillor Alan Robins had chosen Leo House as one of his 'charities of the year'. The five charities met and decided to all work together and split the proceeds between us. The impact of the Coronavirus pandemic meant monthly meetings were held on Zoom. Several events were arranged but due to the pandemic restrictions, subsequently cancelled. In place of those cancelled events, we held online quizzes and a fantastic virtual murder mystery by Southwick Players.

Alan was asked to be Mayor for another year (until May 2022) and he retained the same five charities. As Covid restrictions relaxed, we were able to arrange outdoor events such as the Boundary Walk and several Guided Tours. The far right picture shows crime writer Peter James at our recent event in the Council Chamber.

We have now come to the end of our two years and are eagerly awaiting the total donations raised during this time. It has been a great experience and we have become good friends. It was a pleasure to work together and learn about each other's charities. My personal thanks to Alan the Mayor; the Mayoralty staff: Minna, Elaine and Robbie for their help and encouragement and support for Leo House.



Who are we?

Leo House was established by Brighton Lions Club to help life-limited children, young people and their families living in East and Mid-Sussex as well as in Brighton & Hove. Leo House supports children and young people with a life-limiting condition from birth to 25 years of age and their families. We know we cannot cure them but we can help to give them the best quality of life for as long as that might be.

Corporate team rise to the challenge to raise vital funds

In order to raise money for Leo House, a team of five from Braddock International completed the Mt. Kilimanjaro Challenge over the course of a weekend. This meant they had to complete a distance of 60 miles, the equivalent to the distance required to reach the summit of the tallest mountain in Africa.

They ran/walked this distance between them, in various locations throughout Sussex, aiming to complete the challenge in the fastest time possible. The team were Dan Phelan, Liam Vickery, Craig Eaves, Phil Davis & Louis Seeshons. Many thanks for the £1240 raised for Leo House at Home.



Thank you!

Thank you to everyone for your generous donations to Leo House including:

- Annie Goodall
- St Cosmas and St Damian Church, Keymer
- Mrs Wilcockson
- Mrs G Tingley
- Hassocks Townswomen's Guild
- Mrs K Curry
- Rev A B Green
- Mrs J F Norris
- Mrs H Walkden
- Ms J Cloake