

Lilly's story

Meet Lilly. Lilly lives in Hooe, East Sussex, and has severe complex needs. Lilly and her family have been cared for by Leo House nurses for over two years, something made possible thanks to you.

"Lilly was born three weeks early, which is classed as full term, so we weren't too worried," explains Mum Paula. "They do the hearing test before you leave the hospital, which she failed. We weren't necessarily surprised about because she was a little early, but then she failed two more. That is when we first knew something was wrong."

"We then noticed that Lilly has reflux issues; she just can't tolerate any fluid by mouth because she doesn't understand what to do with it. Lilly is fed directly into her stomach but also has pureed food, not too watery and not too lumpy. Anything that I make that can be pureed, Lilly has – she has Christmas dinner with us which she loves!"

Paula is Lilly's full-time carer and, despite having non-stop hospital appointments throughout the past seven years, still doesn't have a diagnosis for her daughter. "We had someone once tell us, 'give her another six months or so and she will probably be walking'. Well, she is seven years old, we know that it is not going to happen. It doesn't matter if we get a diagnosis or not, it is not going to change anything. In my eyes, she is perfect as she is."

Lilly is unable to sit up on her own. "She has lots of floor time and she manages to move around in circles, she

can move front to back rolling over, she can move from one side of the room to the other – I still don't know how she does it!"

Susan, a Leo House funded Care Support Worker, visits regularly to take care of Lilly whilst Paula spends some quality time with her oldest children, Erica, 14, and George, 11.

During the August summer holidays, Susan took Lilly out for a day of adventures whilst Paula spent some time with her eldest children. "It is really nice to have time with the older two," Paula says. "They don't get as much time from me as I'd like to give them. When Susan is with Lilly we can do anything; go to the cinema, stop for lunch, anything that is just us three really."

"The care we get, thanks to Leo House, is amazing. It really is. There is always someone on the other end of the phone. If there's a problem the team always come up with something, even if that is just pointing us in the right direction.

"They are brilliant, they really are, and they need all the help and support that they can get so they can continue doing what they do for us. It would be heart-breaking if I was told that they were going to get taken away from us. I don't know what we would do."



Looking ahead

Don't forget to let us know of any forthcoming fundraising events in aid of Leo House at Home.

Contact us

Leo House, Lions Dene, The Deneway, Brighton, BN1 5AZ

- telephone 01273 556834
- www.leohouse.org.uk
- email info@leohouse.org.uk

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This organisation raises money and awareness on behalf of all the 12 hospice charities in Sussex. The picture shows representatives of each at the recent AGM with the latest donation. Richard Lintott, our Chairman, is top right.

Fascinating toys

Toy maker, John Alden, has been a supporter of Leo House from its beginnings. He designed the original Leo House logo. Recently he has kindly donated the proceeds of exhibitions of his miniature toys.

John's varied artistic career has included miniature painter, cartoonist, antique dealer, dolls house restorer and maker of dolls house furniture, as well as performing as a story teller. He is inspired by the late Yootha Rose, who made toys for the royal family in the 1950's.

His next exhibition is at the Crypt Gallery, 23 Church Street, Seaford, 2 – 28 November 2019, Monday – Saturday, 10am – 4pm, excluding Wednesday, and Sunday,



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.

Thank you!

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

St Barnabas Tuesday Club
Miss J Norris
M Kendall
Farrington Property Development
Adur East Lions
Miss J P Shepherd
Mrs B Cheesman
Miss Allard
Mr J Harman
Ms S Jenkins

Don't forget, Leo House at Home spends almost all of this money to fund our nurses, less than 2p in the £ goes to pay expenses.

Geoff Edwards



We are sorry to report the death of one of the founders of Leo House. Geoff served as Chairman for several years before stepping down due to health problems. Geoff had no family and bequeathed his house to Leo House at Home. This was an extremely generous gesture from a very charity-minded friend.

We are very happy to receive any legacies, no matter how small or large, as our entire operation depends on donations from the public. All monies go to fund nurses for the life-limited children of Sussex.

More information about legacies is on our website in the Legacies section.