

Fia's Story

Leo House cares for children in Brighton & Hove and across East Sussex in the comfort of their own homes. One of the youngsters receiving this care is four year old Fia, a happy, stubborn and cheeky little girl who loves life and loves people, according to her mum Lian.

Fia was diagnosed with Alexander Disease, a degenerative neurological condition, at the age of two and a half. There are only around 100 cases of the disease worldwide, so Fia and her family don't really know what to expect, but they do know that children with the disease tend to live to about six or seven years old. This makes the time they have together even more precious.

The charity's Community Team visit Fia and her family at home, taking Fia out for a few hours or staying home with her whilst parents Matt and Lian enjoy some precious time together. "Fia adores Heidi, her Care Support Worker," says Lian. "She won't just go with anybody but she trusts

Heidi, she looks forward to her coming round. They have a really special bond which is lovely to see."

Crucially, Heidi supports the whole family whilst she is visiting. She will have a chat with Lian and Matt about any concerns they might have, she might point them in the direction of other services or suggest new ways of doing things. The Community Team can also advocate for families if they wish. "The nursing support is hugely beneficial," says Lian. "I could theoretically be making five different phonecalls to different medical professionals but Heidi can co-ordinate that so I only have to make one."

"Knowing that we only have our daughter for a short time, having this care at home has just given us the confidence to go on," comments Matt, "I can't tell you how much it has meant to have their support, it is absolutely priceless."



Looking ahead

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

Contact us

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Christmas Fete

It was a great start to the festive season with £380 raised on Saturday 18 November at the Hurstpierpoint Christmas Fete. There were lots of activities for children, art and crafts, refreshments and a raffle all in support of Leo House at Home. Many thanks to everyone involved.



Decluttering?

Are you tired of having nowhere to put anything? Are your cupboards bulging with stuff you no longer need but it's too good to throw out? We sold a serviceable lawn-mower to friends for a Leo House donation of £20. We got some space, they got the lawnmower, and our nurses got £20! Let us know if you can do something similar.



SUSSEX
HOSPICES
TRAIL



Leo section of Hospice Walk is celebrated

The Sussex Hospices Trail is a series of walks dedicated to raising awareness of hospice care in Sussex. On 23 September, Friends of Sussex Hospices organised a celebratory walk of all 200 miles of the trail. Teams took on one of the 26 parts. Each section was formally started simultaneously by volunteers from the hospices and completing teams were greeted with a medal as a memento of the day. Our photo (above) shows successful walkers arriving at Brighton Station with a marshal from Leo House at Home.

The Leo House section was walked and digitally logged by some of the Trustees and supporters last summer. Our route goes from Brighton Station to Southease, a total of just over 11 miles. We had to carefully follow the trail and save it into a smartphone so it could be uploaded onto an app for walkers completing the route in the future. We also wrote down directions for the non-app public, as well as recording interesting features along the way. At the end of our trail at Southease there is the new YHA with a fantastic café serving all manner of food and drink. This was a very welcome stopping point!

For further information about the trail and how you can walk through beautiful Sussex scenery, maps can be downloaded from iFootpath website or via their app.



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:

Brighton District Nursing Association
Mrs M Kendall
Woodingdean Methodist Ladies
B Millar
A Baker
Hassocks Townswomen's Guild
W Goddard
K Fakes
Mrs D Mephram
Stephen George Danahar Memorial Fund

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