

Aimee's Story



Nine years ago Marie Baker and her husband Martin welcomed their beautiful new baby girl, Aimee, to their family. After an easy pregnancy and normal birth they were over the

moon to bring their perfect, healthy little girl back to their family home in Eastbourne.

Their world was turned upside down, however, when Aimee had a seizure at just 4 months old. By 9 months old Aimee was diagnosed with Dravet Syndrome, a rare form of epilepsy that affects every area of her life.

A contented little girl, Aimee "lives in her own little bubble" according to mum Marie. "She is a happy child who adores her sister and loves school." But her condition means that

Aimee suffers seizures on a weekly basis, often having 6-8 fits in the space of a few hours.

Aimee is mobile, but unsteady on her feet. She can communicate but is unable to speak and has a severe learning disability. She is also tube-fed, in nappies and has a strict medicine routine to control her condition.

For the first four years Aimee would have a seizure every 7-10 days. It would last up to an hour and result in her being hospitalised for 4-5 days at a time, putting a massive strain on family life.

Looking for some respite from the demands of caring for a child with such an unpredictable condition, the family were referred to Leo House at Home. They started receiving regular visits from one of the Community Nurses, who takes care of all of Aimee's needs whilst the rest of the family enjoy activities that are usually out of bounds for them. Marie explains, "I would never usually

go to the cinema because I would be terrified to turn my phone off for 2 hours and focus on anything other than Aimee. But with Laura, our Community Nurse, I can do just that."



And the help goes beyond respite. Marie continues, "recently we needed a car seat for Aimee but the one we needed cost £1,700. Laura stepped in and helped us to complete a charity application for funding, which was successful and means that Aimee can now travel with the family in safety."

"It really is fantastic knowing that we have the support Leo House. We have been given the opportunity to build a really strong relationship with our Community Nurse, something that doesn't often happen with other care providers. Laura knows Aimee and us so well, I know she will look after her with the same care and attention that I would."

Please help us support other families like Aimee's.

Thank You Fred, RIP

Sadly we have lost one of our best supporters, Fred Coombs. Fred loved children and gave generously to Leo House from the start. He has kindly left us a donation in his Will and family and friends have raised another £150 in his memory. Here, we pay tribute to this generous man.

Born in 1926 in South East London, Fred was evacuated to near Midhurst. A bright boy, he left school at 15, joining the Air Training Corps in 1941. He was also in the Home Guard and the Fleet Air Arm, serving as an aircraft mechanic in Ceylon and Egypt.

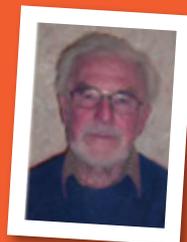
In his 20s and 30s Fred enjoyed wrestling, weight-lifting, canoeing, swimming and cycling. He once cycled over the Pyrenees and was still a keen cyclist and swimmer in

his late 70s.

He met his wife, Sylvia, on a cycling trip to Newhaven. Married in 1959, the couple were together for 46 years and had 3 children and 4 grandchildren of whom Fred was incredibly proud.

Later, Fred worked as an electrical fitter, spending his days out in his van, picking blackberries, drinking tea, watching the birds and, of course, doing his work.

He was a great DIY-er, helping others without asking for a penny in return. He was out-going, made friends easily and would talk to anyone. He spoke his mind and was, by all accounts, a bit of a flirt too!



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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Brighton, BN1 5AZ

• Telephone: 01273 556834

• www.leohouse.org.uk

• email info@leohouse.org.uk

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Meet Laura, Leo House at Home Community Nurse

Laura qualified as a paediatric nurse in 2007. During her training she worked with special needs children. She is currently caring for 17 children and young people. As well as providing care at home, her job also includes accompanying families to hospital appointments, attending meetings and visiting schools to offer support to children to help them get the most out of their education, either at school or at home.

As a Community Nurse, Laura is also part of the 24 hour on-call team for children needing end of life care, helping to support the child and their family through this very difficult time.

Laura said, "I love my job and I love what I do. You always learn new things on this job and every family is unique. There is no typical day but that's what makes the job so fantastic. It is such a privilege to care for these children and provide support for their families."



Ovett's Bring Home the Bacon for Leo



Dave Ovett and his family have run their bacon and egg business in Brighton for over 55 years. They have a stall in the new Brighton Open Market off the London Road. The family and their customers have been generous supporters of Leo House for many years and we look forward to their help in the future. Do come and visit them and sample their new range of cheese and deli products, all at keen prices!

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.

What's New for Leo House at Home?

- There will be a Leo House at Home stall at the Lions Craft Fair at Lions Dene, The Deneway, Brighton from 10am on Saturday November 29th.
- Next June the Friends of Sussex Hospices are running their 'Hymnathon' at Lancing College. This is a 30 hour event where local choirs are sponsored to sing for a small part of the time. If you or a friend belong to a choir and you would like to join in, please contact us.
- If you liked Fred's story and would like to leave a gift to Leo House in your Will, we'd be delighted. If you have questions see our website or call us.
- Next March we are joining the Hospices Mad March Pub Quiz, if your local would like to get involved, let us know.

Ryle House Special Event

Here at Brighton College each of our houses supports a nominated charity. Ryle House has been associated with Leo House at Home for around ten years now, and the 80 boys that make up the house enjoy learning about and supporting the work that Leo House does.

Each autumn, we entertain the parents of the boys in the house with a gala fund-raising evening, which is known as 'Ryle at Home'. All of the boys are involved, whether it be as a waiter or a solo musician. We hosted 75 parents this year, who were treated to a wide range of acts, from singers to a whole House performance of 70s hit 'Hooked on a Feeling'.

It is all a fine opportunity for the boys to use their talents to raise as much money as possible. This year we had a raffle, with some superb prizes from a day out in a chauffeur-driven VW Camper to a two-ball round of golf at East Brighton Golf Course. The raffle raised over £500 and was our most successful ever. We also auctioned off two tickets to see England play Australia at Twickenham this autumn. Bidding was feverish and, as a result, we raised a further £450.

We look forward to being able to hand over a cheque for over £2,000 soon, which will represent the total raised for Leo House this term.

Gary Mitchell, Housemaster – Ryle House, Brighton College

Thank you!

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

Mrs M Knowles
Miss A H Allard
Mr and Mrs N Tate
Mr P Poplett
Uckfield and District Lions Club
Mr & Mrs K Cronin
Ovingdean WI
Mrs B A Tapp
Mrs S Ross
St Wulfran's Church
Miss J P Shepperd

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.