

Madison's Story

Bubbly, cheeky and stubborn are the three words Lisa Wain uses to describe her eight year-old daughter Madison. And these characteristics are probably exactly what has made Madison the delightful fighter she is today – defying all the original odds, as doctors said she would never be able to walk or talk due to her weak heart.

Lisa and husband Andy first discovered that their baby had a cardiac problem at the 20-week scan. Lisa was monitored closely and was then taken into St George's Hospital in London to have Madison after she was showing signs of deterioration. She was then rushed to Royal Brompton Hospital.

The initial weeks and months were extremely difficult for the new parents, as their baby daughter was diagnosed with Dilated Cardiomyopathy, a condition which means that the heart cannot pump blood efficiently, which in turn can affect the lungs, liver and other body systems.

Madison suffered from severe reflux, and her weak heart meant that she used a nasogastric tube for feeding and medication until she was two. However, the reflux and vomiting continued so the doctors switched her to a gastrostomy –

a feeding tube inserted directly into the stomach.

The doctors told Lisa and Andy to take one day at a time, but that it was unlikely Madison would ever be able to walk or talk.

Madison required 24-hour care, and was in and out of hospital, but their lifeline came in 2012 when they received a referral for hospice care. The family receives support from Amie, one of the community nurses funded by Leo House. "Madison has special bond with Amie and loves going out and about with her. It allows me time to get on with everyday things that I otherwise wouldn't have the chance to do," says Lisa. "Our family and friends are really helpful and supportive, but the situation with Madison's feeding and medication through a gastrostomy sometimes makes people uneasy. Having Amie here is a lifeline and means we can all relax."

While she is still in and out of hospital, to look at Madison, you wouldn't think there was anything wrong. But recent deterioration to her heart has meant that doctors have had to increase her heart medication, and Lisa and Andy are aware that they could one day be told that she needs a heart transplant. In the



meantime, they are still following the original advice they were given when Madison was born of taking one day at a time. But they are also watching a determined, delightful little girl continue to grow and defy all odds.

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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Mad March Pub Quizzes

The annual quiz season saw four quizzes for Leo House at Home. Keen quizzers at the St Barnabas Tuesday Club, East Brighton Golf Club, Brighton Marina Yacht Club and Ovingdean Village Hall raised almost £1,000 from entry money and raffles. Our photo shows a scene from the golf club quiz.



Masons Cement Support

Our picture shows Bob Mulvey, Provincial Grand Almoner from Sussex Masonic Charities, presenting cheques recently. Freemasonry is one of the world's oldest and largest non-religious, non-political, fraternal and charitable organisations. They are particularly supportive of the ongoing work of hospices and fund running costs, not capital investment.

Our grateful thanks go to Sussex Masonic Charities for a donation of £1,500 and the Masonic Charity Foundation for £500.



Peter Donates His Scary Hair

East Brighton golfer, Peter Baker, decided to sacrifice his scary hair on behalf of Leo House at Home, the Captain's charity for 2018. One of the lady members offered to do the deed in front of some of his friends, who had all sponsored him. The before and after pictures tell their own story! Thanks to Peter who raised over £700.

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.



Max raises over £800 at the Brighton Marathon

Max Fairfield from Ryle House, Brighton College, says:

"I'm not even a very good runner but... I think raising money for Leo House is something incredibly important.

"Leo House do amazing work in improving the quality of life for life-limited children, young adults and their families."

Thank you Max!



Thank you!

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

Mr & Mrs Copelin
The Parish of Clayton with Keymer
Mrs J Tuppen
Metal Box Pensioners Association
Ms M Jones
Bobbie Cheesman
Mrs P Fogg
Stephen George Danahar Memorial Fund
Mr A Baker
Brighton Lions Club

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.