



COUPLE TRANSFORM HOME FOR BRAVE DAUGHTER

A couple from Wigan spent more than £50,000 of their life savings to transform their home and make life easier for their daughter who has a rare skin condition requiring laser treatment leaving her with ‘polka dots’ all over her face.

“She is our little miracle. We wanted the best for her and to make her life easier”

Paul and Rebecca Callaghan have made huge changes to their three-bedroom semi-detached property in Leigh to help Matilda, who suffers from a rare neurological and skin disorder called Sturge-Weber Syndrome and almost died when she was born.

Matilda, who was six last month, has a rare birthmark which covers all her face and the right side of her body and has regular laser treatment to stop it from growing. The distinct ‘polka dot’ marks are bruising caused by the lasers which burn the blood capillaries under her skin to prevent the mark from growing and becoming deformed.

The birthmark is also internal, so it affects Matilda’s brain, eyes and gums. She may have to have treatment every two months until she is 16 to prevent the birth mark from growing.

SWS, which affects around 14 children in the UK every year, has caused the little girl visual impairment, epilepsy, glaucoma and paralysis in her left side.

Matilda was also born with two holes in her heart and a pouch in her throat and required life-saving surgery when she was a baby. She also has digestion problems caused by Tracheoesophageal Fistula which means she was born without a tube from her throat to her stomach, so doctors had to build one for her.

Matilda has had more than 30 operations and is due to have more laser treatment on her face this month. Wife Rebecca is Matilda’s full-time carer.



The Callaghan's have spent thousands on extending the upstairs of their home and putting in a sensory room – a special room designed to develop Matilda's sense through special lighting, objects and music – a bedroom and wet room. They have also built a completely new kitchen which has been designed around the focal point of the room – Matilda's unique homelift, manufactured by UK-based company Stiltz Lifts, which Paul found online.

The Callaghan's wanted to make their home as 'accessible as possible' for Matilda but did not want to turn it into a house with 'stereotypical disabled products'. The innovative homelift is a good example of this. At a cost of around £14,000, the customised Stiltz Trio Homelift is compact but spacious enough to accommodate Matilda's four-wheel Veldink Kiddo Classic children's wheelchair which the family bought after raising £5,000 earlier this year via GoFundMe.

The project's taken the Callaghan's almost 18 months to complete but Paul says it's been worth every penny to make life as comfortable as possible for Matilda.

Paul, 50, is a builder by trade, so did a lot of the work on the house himself which helped to keep costs down. The £50,000 cost of the renovation works has come from the Callaghan's life savings with some help from Wigan Council.



He said: "We wanted to make the house as accessible and normal as possible for Matilda without turning it into a disabled house.

"Matilda has multiple disabilities, but we didn't want to highlight that. The style of the homelift is not obviously for disabled people and shies away from the prejudice towards people with disabilities. It is something we can all use.

"I'm in the building trade so did a lot of the work myself. Now it's finished, it seems a world away from where we were three years ago. We've got a long way to go and Matilda has many complications, but we know more about her problems now than we did then.

"Matilda has had more than 30 operations and is so brave. She is our little miracle. We wanted the best for her and to make her life easier".

"We never thought she would make it when she was first born so we have come a long way. The changes we have made to the house – especially the lift which has made a massive difference as she is getting heavier now – have all hopefully made Matilda's life more comfortable".



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