

Charlie became seriously ill 4 years ago when she was 23 whilst studying for her master's degree. She first suffered a blood clot in her lung but also started displaying many symptoms including serious problems with her digestive system and severe pains in her back. After years of investigations both through the NHS and self-funded private appointments, she was finally diagnosed with Hypermobile Ehlers-Danlos Syndrome (EDS) a poorly understood, rarely diagnosed connective tissue disorder which affects every system in the body.



This has resulted in Charlie being diagnosed with multiple comorbid and disabling conditions. Gastroparesis, which affects her gastrointestinal system, Endometriosis which affects her reproductive organs, POTS an autonomic nervous system and heart condition and Mast Cell Activation Disorder which puts her body in an almost constant state of allergic reaction. Hypermobile EDS causes her joints to be very loose and unstable. As such Charlie has almost daily joint dislocations in any joint in her body.

Due to the complicated nature of the condition Ehlers-Danlos Syndrome is considered by specialists to be 'the most neglected illness in modern medicine'. As it can strike any system in the body and can affect patients on a spectrum of severity, there is no centralized care and patients are often left without any comprehensive treatment plan. Charlie is treated under 7 different departments, across 5 different hospitals with little communication between them and most of these departments deny responsibility for her care.



In the last year, Charlie's condition has deteriorated rapidly, and she has developed instability in her upper spine causing Cervical Medullary Syndrome (brain stem compression) a rare, life-threatening and extremely debilitating complication of Hypermobile Ehlers-Danlos Syndrome.

Charlie can now spend little time in an upright position and then only with the aid of a neck and back brace. She does occasionally venture out to appointments with the aid of an electric wheelchair and the help of her partner Oscar who has been a wonderful support throughout and is now her full-time carer.

Charlie's cervical spine (neck) is extremely unstable, her vertebrae partially dislocate when she moves her neck and are at risk of a full dislocation which would be fatal. She needs a fusion of her entire cervical spine to prevent this from happening. These surgeries are performed routinely in America but are currently not available for patients with Hypermobile Ehlers-Danlos Syndrome in the UK.

We met with Dr. Gilete a skilled Neurosurgeon in Barcelona on the 21st January 2019. Dr. Gilete specializes in spine stabilization for severe cases of instability in Ehlers-Danlos patients. He is regarded as one of the best surgeons for this complication in the World by the international Ehlers-Danlos community. After many tests, scans and a thorough examination he concluded that Charlie's instability and brain stem compression is severe and that she needs a full cervical fusion urgently.

Left untreated this will cause seizures, paralysis, blindness or may be fatal. Charlie already experiences severe neurological problems such as aphasia, memory loss, speech and movement problems, Cerebral Spinal Fluid leaks and occipital neuralgia (also known as the suicide headache). If Charlie sits upright for too long, she loses the ability to walk, speak, swallow and becomes very confused. She has sometimes even lost her vision or struggled to breathe. The longer Charlie is left without this surgery the more likely it is that these issues will become permanent.

The current quote for the cost of the surgery is £60,000 and we have already raised almost half of this through the generosity of friends and relatives and several fundraising events; we are currently planning more. This is where you come in, whether this is through donating or sponsoring us in one of the events we will be organising or indeed holding a fundraising event of your own.

We will be eternally grateful for anything you can do to help support us as we try to campaign to save our Charlie's life.

If we can fund this surgery and get Charlie's life back, she is planning on using her experiences to raise awareness and campaign to change the situation in the UK for future patients.

For more information on how to help visit our website: www.chance4charlie.com

You can also contact us for more information

Email: chance4charlie@outlook.com

If you are on social media you can follow Charlie's journey and share Charlie's story to help raise awareness:

Follow #Chance4Charlie

Twitter: @_chance4charlie

Instagram: @chance4charlie

Facebook: @chance4charlieupdates

Donations can be made via:

JustGiving: www.justgiving.com/crowdfunding/chance4charlie

Paypal: <http://www.paypal.me/chance4charlie>

Bank transfer:

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s/c: 07-08-06