



5 April 2017

Teenager reaches out for support to battle invisible illness

On the outside, teenager Emily Drummond looks like your average 17 year old.

She's bright, articulate and funny and like many young people her age, she enjoys spending time with friends and can't wait to get her driver's license.

Behind the surface though is a debilitating illness that leaves Emily gripped with chronic pain almost daily as a sufferer of Ehlers Danlos Syndrome.

The syndrome is a group of disorders that affect the connective tissues that support the skin, bones and blood vessel walls in the body, and many other organs and tissues.

Passed on through genetics and dubbed as the 'invisible illness' by sufferers, Emily falls in the range classified as: Hypermobility Type.

Symptoms include overly flexible (hyper mobile) joints, stretchy skin and frequent dislocations resulting in musculoskeletal pain. As a precaution, Emily is checked by a heart specialist every 12 months for possible blood flow complications to the heart.

Earlier this year, Emily made the decision to reduce her Year 12 workload by dropping several OP subjects because the physical tasks associated with attending school were becoming excruciating.

Emily said it was a tough decision to make, but a necessary one as specialist appointments and the chronic pain took its toll on her school attendance.

"It's hard to sit down in the classroom for an extended period of time when your body is filled with pain from your joints," Emily said.

"The constant pain affects my concentration and can make it really difficult to learn. Simple things like standing up can be challenging as is walking between classrooms.

"Carrying my school bag became a real issue because I just couldn't support the weight on my shoulder.

"Thankfully my school has been very supportive and has made adjustments for me, like letting me do my exams in a separate space so I can get up and move around for example."

Emily started experiencing hyper-mobility of her joints around the age of six, but it wasn't until she was 14 that a paediatric rheumatologist diagnosed her with Ehlers Danlos Syndrome.

Emily's mother, Belinda Drummond, remembers the moment and said it was a relief to know what was causing the pain and what they could do about it.

"Emily was a talented dancer and competitive swimmer when she was younger, but she's had to give these things up, which has been hard to watch as a parent," Mrs Dummond said.

"What's really difficult is the response we sometimes get from people who don't understand how debilitating this condition is, who assume Emily is a hypochondriac.

"That hurts and adds to the social isolation and stigma many people face with this illness," Mrs Drummond said.

Emily is a fighter though and refuses to let Ehlers Danlos Syndrome rule her life.

At the recommendation of her psychiatrist after a knee operation, Emily signed up to the Help Outside School Hours Program run by St Vincent's Private Hospital Brisbane.

The small group adolescent program, run one afternoon a week after school for a term, is the only one of its kind in Queensland.

The program helps young people better manage chronic pain through a self-management approach and is supported by a multi-disciplinary team which includes pain specialists, allied health professionals and clinical nurses.

Clinical psychologist Dr H. Karen Li says the goal of the program is to help young people get back to doing the things they enjoy and to strive for the future they want.

"We help young people be more active managers of their condition by giving them the confidence and skills to cope with their pain, and develop a plan to help them reach their goals," Dr Li said.

Emily says the biggest benefit of the program was meeting others her age who could relate to her situation.

"It's been a great social support network for me and my family knowing that I'm not alone," Emily said.

"What's really helped too is learning techniques to manage my pain, like recognising and knowing my limits and then having a plan for that scenario."

Since completing the program, Emily has become an Austswim teacher and has a job after school teaching learn to swim classes for under-fives on Brisbane's south side.

“I’ve recently had further knee surgery and a procedure on my back to ease my back pain and that has been challenging,” Emily said.

“But I’m feeling confident and positive in managing my pain and I’ll keep pushing forward.”

It is estimated Ehlers Danlos Syndrome affects 1 in 5,000 individuals world-wide¹.

For more information about the Help Outside of School Hours Program (HOP) phone 3240 1770 or visit www.svphb.org.au/home/our-services/adolescent-pain-management. For more information about Ehlers Danlos Syndrome, visit the Ehlers Danlos Syndrome Society page on Facebook.

Media enquiries:

Maryanne Kepui / St Vincent’s Private Hospital Brisbane / 3435 1615 / maryanne.kepui@svha.org.au

Available for interview/photos: Emily Drummond

¹ <https://ghr.nlm.nih.gov/condition/ehlers-danlos-syndrome#statistics> viewed on 5 April, 2017



Image: Emily Drummond doesn’t let her condition stop her from achieving her goals like becoming a swim teacher.