

Life with a hidden illness: young Harwich woman's campaign to support people with ME

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Fixer Ashleigh Lovett loves music and sport, but two years ago she was struck down with an illness that made following her passions much more difficult.

"When I was 15 I began to get headaches, tiredness, and had no energy. I lost the use of my legs and had to be admitted into hospital where I was treated for suspected meningitis," says Ashleigh.

"After two weeks I was sent home and I gradually improved. But soon I declined again and that's when my consultant gave me the diagnosis of ME."

The 17-year-old from Harwich is now working with Fixers, a charity which supports young people to 'fix the future', to show teenagers what life with ME is really like and to give others with the condition support.

Jane Colby, Executive Director of The Young ME Sufferers Trust, explains: "ME stands for Myalgic Encephalomyelitis; these days it tends to be called chronic fatigue syndrome.

"Classic ME has always been known as virally triggered. It is the most common cause of long term sickness absence in school from children and in teachers.

"ME can affect anyone, but there is a peak in the middle years, there's another peak in the early to mid-teens and you do tend to find more girls than boys with the condition."

Ashleigh wants people to understand how difficult it can be living with the condition.

"You never know the next day is going to be like; you don't know if you're going to be well or if you're going to be bed bound.

"The fatigue is one of the main factors, and heavy limbs and painful legs.

"People didn't believe I was ill at first as there is no physical sign of it. People used to say I was spoilt and lazy, which hurt me.

"To make people understand how I am feeling I want to get people to wear weighted suits so they can experience for themselves how it feels to have ME"

Ashleigh spoke to fellow ME sufferer Jodie Cleary, 19, and from Chelmsford, about her project.

"I was diagnosed when I was 11. No one believed me; until I was diagnosed, and still after that, people would just go: 'get up, you're fine, put some clothes on'," Jodie says.

"But for someone who has ME, even to stand in the shower for seven minutes could be awful.

"To get better, I needed support. I needed people to say: 'It's okay, I had it and guess what, I'm married now and I've got kids'. I needed other people to tell me that I could get out of this hole."

Ashleigh hopes her project will help stop other people from feeling isolated like she did.

"I really hope my Fixers project will not only help ME sufferers know that they're not alone and there is help out there, but also educate the general public about the condition."

Fixers is charity which supports young people across the UK to take action and change things for the better, addressing any issue they feel strongly about.

How each Fixer tackles their chosen issue is up to them – as long as they benefit someone else.

The award-winning Fixers project has already supported over 9,000 young people to have an authentic voice in their community.

Each Fixer is supported to create the resources they need - such as films, websites or print work - to

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make their chosen project a success.

Now, thanks to a grant from the Big Lottery Fund, Fixers aims to work with a further 19,000 young people over the next three years.

For images, interviews or more information, please contact Sue Meaden in the Fixers Communications Team by email sue@fixers.org.uk or phone 01962 810970.

There are lots more stories about young people doing great things on the Fixers website, Twitter and Facebook pages:

<http://www.fixers.org.uk>

<http://www.twitter.com/FixersUK>

<http://www.facebook.com/FixersUK>

Notes to editors:

- Fixers started in England in 2008. Now with a £7.2 million grant from the Big Lottery Fund, Fixers is extending into Wales, Northern Ireland and Scotland. To date, over 9,000 young people across the UK have become Fixers and created 1,040 projects.
- The Public Service Broadcasting Trust is a charity that brings together mainstream broadcasters, public and voluntary sector services, and viewers.
- The Big Lottery Fund (BIG), the largest distributor of National Lottery good cause funding, is responsible for giving out 40% of the money raised for good causes by the National Lottery.
- BIG is committed to bringing real improvements to communities and the lives of people most in need and has been rolling out grants to health, education, environment and charitable causes across the UK since June 2004. The Fund was formally established by Parliament on 1 December 2006.
- Since the National Lottery began in 1994, 28p from every pound spent by the public has gone to good causes. As a result, over £29 billion has now been raised and more than 383,000 grants awarded across arts, sport, heritage, charities, health, education and the environment.
- Margo Horsley, Chief Executive of Fixers says: "Fixers started in 2008 as just an idea... an idea given a voice by over 9,000 young people over the past five years. They have reached thousands of people with their work, on a national stage as well as in and around where they live. They choose the full array of social and health issues facing society today and set about making their mark. Fixers are always courageous and their ideas can be challenging and life-changing, not just for themselves."
- Peter Ainsworth, Big Lottery Fund UK Chair, says: "The Big Lottery Fund is extremely happy to be supporting Fixers to engage with more young people to change things for the better. Thousands of public-spirited young people across the UK are campaigning to make improvements in their own communities. By providing a platform to highlight their voluntary work and many achievements, Fixers demonstrates the positive contribution thousands of committed young people are making at a local level and challenges negative stereotypes."

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