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Tackling narcolepsy

DESPITE DEALING WITH THE NIGHTMARES CAUSED BY HER CONDITION, APRIL-SCARLETT LEE'S CARTOONS HAVE GONE GLOBAL AS PART OF PROJECT SLEEP.
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Real lives

yourhealth

YOUR NHS

DR CARL ELLSON

Clinical Lead,
NHS South
Worcestershire CGCKnow what
to do when
you are ill
or injured

ALTHOUGH winter is traditionally seen as the busiest time for emergency departments, summer can also see high attendances at A&E, so it's important to remember there are a number of alternative NHS services available to treat you if you're injured or unwell this summer.

As people get out and about to enjoy the summer weather there are a range of health problems that summer can bring including hay fever, insect stings, bites or an upset stomach from the barbecue.

None of these require a visit to A&E and can all be treated with self-care or by seeking advice from other sources, e.g. your local pharmacy or NHS 111.

The 'Is A&E for me?' campaign launched back in October 2013 to help ease the pressures on emergency departments by educating people to make sure they are aware of their options when thinking about going to A&E. This means people who are in genuine need of emergency treatment can be seen in good time, which can help to save lives.

Here in south Worcestershire, I have been encouraged that many people I have spoken to about the campaign have been very positive about it and are aware of their options.

An easy and convenient way of getting information about local health services is by downloading the mobile app, which has been launched by the three Worcestershire Clinical Commissioning Groups.

The app includes a GPS function to find your nearest NHS services.

We're keen to hear your feedback on the app, and you can let us know by emailing ccgcomms@worcestershire.nhs.uk.

More information about the campaign and how to download the app can be found on isaandeforme.com. The app is also available to download directly from Google Play or the iTunes app store.

Why I've drawn on my experience to highlight this nightmare disorder

Diagnosed with narcolepsy as a teenager, April-Scarlett Lee has struggled with symptoms caused by the condition. But LYDIA JOHNSON finds out how her creativity has made her cartoons famous around the globe

"MENTAL health can be just as debilitating as being in a wheelchair or on crutches.

"Just because you can't physically see illness from the outside it doesn't mean that person can function any better."

These are the words of 27-year-old April-Scarlett Lee who was first diagnosed with narcolepsy – a rare sleep disorder – when she was just 13.

Symptoms include excessive daytime sleepiness, cataplexy, hypnagogic hallucinations, sleep paralysis and automatic behaviour.

While not all narcoleptics have every symptom, April suffers from them all.

"Excessive daytime sleepiness is basically forever feeling like you need to sleep," April, who lives in Warndon Villages, says.

"Sometimes you don't even want to sleep but you end up doing it without realising.

"I can be having a conversation, eating, reading a book, or just walking around and it just happens.

"People who don't know me will assume I'm just being lazy, I'm bored or even drunk.

"I can feel so tired it physically hurts my body if I don't give in.

"Cataplexy is when your body gets paralysed and you drop to the floor. This is triggered by emotions such as laughing, happiness, sadness, anger or shock.

"With me it seems to happen for no reason. I'm totally awake and I know what's happening around me, I just can't move or speak."

One would hope that most people would stop to help a young girl lying

in the street, but April says this isn't always the case.

"I have had a few people step over me while I am having a cataplectic fit.

"Once I was approached by a woman asking for charitable donations in town. Feeling anxious, I collapsed and she casually stepped over me and moved on to someone else.

"I once collapsed outside college on my way home and a girl talking on her mobile phone stepped over me and actually stood next to me while she carried on talking. Two hours later my dad came looking for me and I was still there."

Before April was diagnosed she battled constantly to prove to doctors that something was wrong with her, as so little was – and still is – known

about the disease.

She says she was once told by a doctor that there was "no such thing as sleeping sickness" and was advised to do some power-walking.

April says she has been mocked, abused by people in the street and kicked off educational courses despite her best attempts to live with a disease that affects less than one per cent of the population.

"It went downhill after I was finally diagnosed. I was still falling asleep at school which caused my grades to fall. No matter how hard I worked I just couldn't keep up. I'm never allowed to drive. I don't have much of a social life because I can't travel alone.

"My narcolepsy has stolen a part of my personality which I am no longer able to express. Instead I dress in bright, wacky colours to express myself. I do get a lot of support from my friends and family, who understand."

April has tried a range of drugs to keep the symptoms at bay so that she can have some sort of life, but says some symptoms are harder to control than others.

"Sleep paralysis and hallucinations go hand in hand and can be very frightening. Before you go to sleep or wake up your brain goes into dream mode. Your body is paralysed and you actually see the things you're dreaming about as though they are real.

"You can hallucinate everything from family members to nightmarish monsters, and they can be so real that you can hear, touch and even smell them.

"The first hallucination I saw was of a man in my bedroom. I've since named him Benny Krueger as he was wearing a striped jumper like Freddy Krueger. He doesn't frighten me anymore but when I first saw him the amount of fear I felt as he slowly moved towards me was horrible. It was like living a nightmare and all you can think about is getting up and turning on the light and shouting for help, but you can't because you're paralysed."

Despite the everyday struggle to stay awake, April socialises with friends when she can, and pursues her love of floristry.

But by becoming involved in a national campaign to raise awareness of the disease, April says she has since made new friends and



FLARE: Not Alone campaign organiser Julie Flygare sporting a T-shirt promoting the initiative featuring one of April's designs.

feels she can positively help others like her.

“I was networking on Facebook with different narcolepsy groups and found the Narcolepsy: Not Alone campaign,” she says.

“The idea was to get people with narcolepsy and their family and friends to take a photo holding the ‘not alone’ sign to show that, although it is a rare illness and not a lot is known about it we are still not completely alone.

“I posted a drawing of myself holding the sign online and people in the campaign liked it, so I started to draw cartoons of other people holding the sign. It was just for fun but the campaign organiser, Julie Flygare, liked my drawings so much she asked me if I would help her by doing an official campaign design.”

April has since seen her drawings printed on to phone cases, mugs and T-shirts which are being worn by people all around the world.

Julie, who lives in the USA, says April’s artwork helped to connect people, with people purchasing the T-shirts in various countries including Japan, Germany and Mexico.

She says: “April generously donated her art work to promote the campaign and benefit my new non-profit organization Project Sleep.”

● To find out more about narcolepsy, visit narcolepsy.org.uk or visit julieflygare.com to learn more about the campaign.



MEMORY: A colourful drawing by April-Scarlett Lee featuring some of the things she has seen during hypnagogic hallucinations.



DETERMINED: April-Scarlett Lee, who was first diagnosed with narcolepsy when she was just 13.



COLOUR: A floral bouquet and headdress created by April-Scarlett Lee. Picture courtesy Hemlock Boutique.

PATIENTS VIEW

PAUL CRAWFORD



Don’t let a barbecue ruin fun in the sun

BARBECUES are an excellent way to unwind and have fun in the summer but they can be disastrous if you get food poisoning.

The main food poisoning bugs cause severe stomach cramps, sickness and diarrhoea with the warmer conditions encouraging these bugs to grow.

Because these germs are only killed by cooking meat until it’s piping hot it is a good idea to cook food through in the oven first and then finish it off on the barbecue to give it the flavour.

Prior to cooking be certain the raw meat pieces are completely thawed. When cooked we need to look at the thickness of the piece of meat to ensure the meat is completely cooked and not partially under done.

When it is taken from the barbecue it can be black on the outside and raw on the inside which can be a recipe for food poisoning. There are many other cause of food poisoning and another danger is cross-contamination – putting raw and cooked meats on the same plates.

The Chartered Institute of Environmental Health have suggested the following additional tips for safe barbecuing:

- Make sure the barbecue is hot enough before you start – the coals should be white hot. Consume the food as soon as possible after cooking;
- Keep food covered and keep perishable food in the fridge until the last minute and always dispose of or refrigerate any uneaten food;
- Experts warn, some of our favourite barbecue side dishes, such as salads, coleslaw and dips, which are left in the sun, can pose a food poisoning risk. Keep cold foods cold and hot foods hot to stop harmful bacteria from multiplying;
- Finally, wash hands thoroughly when handling food.

Enjoy a safe barbecue and have a great summertime.