



HIGHLIGHTS

Recovering from COVID-19

For some, COVID-19 symptoms continue for months.

Fortunately there are some steps that may help one to recover faster.

PAGE 2

The dangers of vaping

Dr Nikita White looks into the health risks of using e-cigarettes.

PAGE 4

ME/CFS sufferers may be working harder at rest

Breakspear Medical patient & graduate presents his findings in his master's thesis.

PAGE 12

Seemingly unrelated symptoms were finally diagnosed

My life-changing diagnosis of Ehlers-Danlos Syndrome

Georgie Windsor is now a university student and has an active life. It is hard to imagine that from early childhood, she suffered from a variety of debilitating health problems, which left her bedbound before the age of 20. She shares her story of the life-changing diagnosis of EDS, which led to help for family members, too.

Hi, I'm Georgie and I'm 22 years old. I'm a student at Cambridge University, a YouTuber, writer, dancer, and lover of the outdoors. However, if you had met me two years ago you would not have even recognised me.

While growing up, I suffered from a variety of seemingly unrelated health problems. As a young gymnast, I was exceedingly flexible

with hypermobile joints. I also struggled with food intolerances and related symptoms. Since I was a baby, I've been unable to digest milk properly. As I grew older, I started to experience more and more symptoms, particularly impacting my digestion, and causing severe fatigue, joint problems, sporadic fainting episodes, and frequent illnesses. Throughout school, I

(CONTINUED ON PAGE 10)

Recovering from COVID-19

Many people who have had COVID-19 experience symptoms that last for weeks or months after the infection has gone. The time it takes to fully recover does not seem to be linked to how ill people were in the first place. For over three decades, Breakspear Medical has been helping patients recover from viral infections and can offer a variety of treatments that may help with your recovery.

This time last year, most people were just beginning to understand that COVID-19 was a global problem. At that time, experts were scrambling to prepare everyone for how lives were going to change for the indefinite future.

Sadly, for some who contracted Covid, their symptoms are ongoing, for weeks and months later, severely impacting their body, mind and lifestyle.

Any viral infection, from mumps to glandular fever or flu, can trigger post-viral fatigue (PVF) and post-viral syndrome. (PVFS).

The symptoms of PVF/PVFS include:

- brain fog/trouble concentrating
- memory/concentration problems
- headaches
- joint stiffness
- muscle pain
- sleep abnormalities
- recurring symptoms of viral infections, such as sore throat, headache and swollen lymph nodes

These are also common symptoms for myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS), which are the common names for a group of significantly debilitating medical conditions characterised by persistent fatigue and other specific symptoms that last for a minimum of six months in adults (and three months in children or adolescents). By using pathology tests, it can often be determined if a patient's ME/CFS may have been caused by a viral infection.

Long Covid is a term for signs and symptoms

that develop during or following a COVID-19 infection, which continue for more than 12 weeks and are not explained by an alternative diagnosis. (See list on page 3 for *Symptoms of long Covid*.)

As with PVF/PVFS, long Covid can affect people of all ages and does not relate specifically to the severity of the initial viral infection.

If you suspected you had Covid and have followed government guidelines, then you will have taken a test to confirm. However, if you did not take a test when the virus was active, or wish to know if you have developed antibodies after vaccination, you could complete an antibody test. Antibodies are the body's way of defending against foreign invaders, such as viruses, bacteria, fungi or parasites, and are created after exposure to protect the body if it is exposed again. Breakspear Medical offers a quantitative at-home antibody test, which measures the antibodies in your blood. COVID-19 antibodies would only be present if you have had Covid or a Covid vaccine.

When the cause of PVF/PVFS has been determined, then one of our doctors can develop a personalised treatment programme.

If a condition continues to burden the immune system, further complications may occur, including a cytokine shift, which compromises the immune system's ability to wipe out viruses and other infections.

A personalised treatment plan would include essential vitamins which can help strengthen the immune system. For example, vitamin C may help to counteract many types of bacterial and viral diseases and may help to reduce the severity and accelerate the recovery from

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severity and accelerate the recovery from respiratory tract infections. A randomised controlled trial supports the theory that vitamin D3 taken daily may accelerate the recovery from bacterial and viral diseases. Research has highlighted that flavonoids including quercetin, heperetin and catechin can be particularly effective in anti-infective activity.

When the immune system attacks the virus and repairs tissues, toxic by-products are created and require elimination through the detoxification pathways. In some people, this can be overwhelming and draining for the body. A detoxification programme involving supplements and infusions and, if possible, sauna or hyperthermia sessions may help.

Mycotoxins, which are naturally occurring toxins produced by certain moulds, may be present and this can be explored.

At this time, there is no research to support specific treatments for long Covid. However, post-viral treatment has broad applicability to multiple viral infections and therefore may benefit those who present with symptoms consistent with PVF/PVFS.

SYMPTOMS OF LONG COVID:

According to the NHS website, common long Covid symptoms include:

- extreme tiredness (fatigue)
- shortness of breath
- chest pain or tightness
- problems with memory and concentration ("brain fog")
- difficulty sleeping (insomnia)
- heart palpitations
- dizziness
- pins and needles
- joint pain
- depression and anxiety
- tinnitus, earaches
- feeling sick, diarrhoea, stomach aches, loss of appetite
- a high temperature, cough, headaches, sore throat, changes to sense of smell or taste
- rashes

The dangers of vaping

by Dr Nikita White

Smoking is bad for your health. While many smokers use vaping to help quit, the habit of vaping can develop in non-smokers, too, for pleasure rather than an alternative to cigarettes. Dr Nikita White writes about the dangers of vaping.



WHAT IS VAPING?

Electric cigarettes, or e-cigarettes, are battery-operated devices that produce a vapour for the user to inhale. Using an e-cigarette is often called “vaping”.

There are thousands of different types and flavours of the e-liquids that are vapourised. E-liquids typically contains nicotine, flavourings, propylene glycol and other chemicals, including carcinogens, such as acetaldehyde and formaldehyde.

E-cigarettes have fallen through the cracks with regards to regulation, as they are not classified as drugs, substances of abuse, nor devices. This means that they do not undergo strict regulations to ensure that they are safe for use, nor do the liquids undergo testing to ensure that the ingredients are safe. In this way, there is no certainty as to what one is smoking when using an e-cigarette, which is proving more dangerous than anticipated.

The NHS currently advocates the appropriate use of e-cigarettes to assist with quitting smoking and studies support this indication. However, people who have never smoked are picking up the habit, most notably youths.

In 2015, the surgeon general of the United States reported that e-cigarette use among high school students had increased by 900 percent and 40 percent of whom had never smoked regularly before. In fact, some people go on to use both tobacco cigarettes and e-cigarettes. Nicotine, which is contained in both types of cigarettes, is an addictive substance and is by no means inert or safe. It raises your blood pressure and spikes your adrenaline, which increases your heart rate and the likelihood of having a heart attack.

Nicotine has also been found to harm adolescent brain development, which continues into the early to mid-20s. Using nicotine in adolescence can harm the parts of the brain that control attention, learning, mood, and impulse control.

Grave concerns have arisen regarding vaping use following various reports of adverse effects related to vaping. Some of the ingredients in e-cigarette

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aerosol could also be harmful to the lungs in the long-term. For example, some e-cigarette flavourings may be safe to eat but not safe to inhale because the gut can process more substances than the lungs. This has become clear in the rising numbers of acute lung injury resulting in some deaths in the USA, where the cases' only risk factor identified was vaping or e-cigarette use. This finding prompted a multistate investigation and request to ban e-cigarette sales.

The e-cigarette aerosol that users breathe in and exhale can contain harmful and potentially harmful substances. These substances include:

- nicotine
- ultrafine particles that can be inhaled deep into the lungs
- flavouring, such as diacetyl, a chemical linked to a serious lung disease
- volatile organic compounds (VOCs)
- cancer-causing chemicals
- heavy metals, such as nickel, tin, and lead

Due to a lack of legislation regulating these devices, the contents of the vapours is not listed. Some vapours, which claim to be nicotine-free, have been found to contain up to three percent nicotine.

A study by *Carporale et al (2019)* found that in a small group of healthy young people who did not smoke or vape, vaping just one nicotine-free e-cigarette produced transient changes in blood vessels similar to those seen in early atherosclerosis. Atherosclerosis is a potentially serious condition where arteries become clogged with fatty substances called plaques or atheroma.

The acute changes seen after one-time vaping (inhaling and exhaling the vaporised aerosol mist from the heated liquid in a battery-operated e-cigarette) suggest that repeated vaping would lead to chronic vascular endothelial dysfunction, the authors of this MRI study state. This is in contrast to the belief that the use of nicotine-free e-cigarettes is safe.

(CONTINUED ON PAGE 6)

BREAKSPEAR MEDICAL IS TAKING CARE WITH COVID-19

No COVID-19 symptoms? Take a rapid lateral flow test

About one in three people with Covid-19 do not have symptoms but can still infect others.

Before attending the clinic, we are asking all patients and visitors to complete a lateral flow test (LFT) for COVID-19 at home on the same day before visiting. (All staff are asked to perform this test on their first shift after a weekend.)

These test kits are free of charge and easy to order online from the government from: gov.uk/order-coronavirus-rapid-lateral-flow-tests or by dialling 119. You may also be able to collect kits free of charge from your local pharmacy.

Your kit should arrive within two days of placing your order. There are seven tests in each kit and full easy-to-follow instructions are enclosed. If the result is positive, we ask that you call us immediately to let us know and do not come to the clinic for your appointment that day. You will need to follow government guidelines relating to a positive result. We will happily reschedule your appointment for a later date.

If you cannot do your own test before you attend the clinic, please let us know and we will perform a rapid lateral flow test for you when you arrive. If this is the case, please allow sufficient time for the test to be carried out prior to your scheduled appointment time.

The dangers of vaping

(CONTINUED FROM PAGE 7)

There have been reports of heart attacks linked to vaping.

A statement published by the Centre for Disease Control (CDC) on 06 September 2019 revealed the following statistics:

As of 6 September 2019, over 450 possible cases of lung illness associated with the use of e-cigarette products have been reported to CDC from the following 33 states and one US territory. These numbers may change frequently, as is evident by the surge in cases from 215 being reported approximately two weeks ago. Of these cases, there have been five deaths, which have been confirmed to be due to vaping or e-cigarette use. It is important to realise that there may be more cases of deaths out there

linked to vaping, but which have not been investigated and/or confirmed as yet.

The CDC is still investigating the ingredients of multiple types of vapours to identify the causative chemical. So far, vitamin E acetate is the current top suspect, as it has been found in multiple samples thus far.

In many of the cases, patients said they experienced a gradual start of symptoms, such as trouble breathing, shortness of breath, and chest pain, before they were brought to the hospital. Some people said they also experienced stomach issues including vomiting and diarrhoea.

At the end of the day, we do not have enough information about what is in the vapours, what is being breathed in, and also what is being breathed out. Therefore, until further information is available, the best advice is to avoid their use entirely.

RECOMMENDED RECIPE:

Easy chicken stir-fry

This gluten-, dairy-, nut-, egg-free, low carb dish is quick, easy and tasty.



INGREDIENTS:

4 boneless, skinless boneless chicken thighs,
chopped into bite-size pieces
60ml tamari sauce
1-1.5cm root ginger, peeled and grated or
finely chopped
5g black pepper

5g salt
5g Chinese 5-spice
30ml coconut oil
300g of your preferred stir-fry vegetables such
as capsicum, pak choi, broccoli, cauliflower
and courgettes

METHOD:

1. Put the chopped chicken thighs into a non-metallic bowl and stir in the tamari sauce, ginger, black pepper, salt and Chinese 5-spice. Let marinate for about 10 minutes.
2. Prepare the vegetables, cutting into similar bite-size pieces.
3. Heat the coconut oil in a hot smoking wok or large frying pan and then add the chicken. Stir-fry for 3-4 minutes, until just starting to brown.
4. Reduce the heat to medium and mix in the chopped vegetables, adding about 100ml of water and cook for several minutes until the vegetables are lightly cooked but not too soft.
5. Remove from heat and serve immediately.

Environmental Medicine Foundation

Registered charity: 1100205

Patient appeal

We are a small number of patients at Breakspear Medical and represent a much wider group who are treated there for illnesses with an environmental cause, such as allergy to and intolerance of foods, pollutants, chemicals, electricity signals and also infectious conditions like Lyme disease.

We have all been coming to Breakspear Medical for some years and our lives, although still sometimes difficult, would be intolerable without the treatment we receive.

Due to our conditions, none of us is able to work, so paying for the treatments we need is a major problem.

That's where the Environmental Medicine Foundation (formerly Breakspear Hospital Trust) comes in. We have all been very fortunate to have benefited from personal financial contributions to our costs made by the charity over a number of years. Without that help, we would have not been able to undergo some of the treatments we desperately need in order to live at least a relatively normal life.

We are very grateful and indebted to all those who have made kind donations to the charity since its inception nearly 18 years ago. The donations have brought big improvements to our lives and to those of many others. We know, of course, that sooner or later, the money could run out. That's why as well as expressing our gratitude, we ask that previous and new donors continue to support the valuable work the Environmental Medicine Foundation (EMF) does and enable us all to carry on with the treatments upon which we so seriously depend.

We recognise that COVID-19 has in some ways affected charity supporters' approach and priorities, but that doesn't mean that our needs and those of many other EMF beneficiaries have gone away.



Thank you all so very much on behalf of all past, current and potential Environmental Medicine Foundation beneficiaries.

R Morgan Davies *Paul Rusu*

Anne F. Holland *Catherine Langan*

Liam McNamara

Rhosyn Morgan-Davies, Paul Rusu, Anne Holland, Catherine Langan and Liam McNamara

How to donate:

Completing the Gift Aid form helps the EMF to claim an extra 25p for every £1 donated.

Post your donation—To send us a cheque, simply complete the enclosed donation form, put it in the self-addressed envelope, put a postage stamp on and drop it in the post.

Pay directly into our bank—you can make a donation in person at the bank or by doing an online transfer.

Bank: Barclays Bank

A/c Name: Environmental Medicine Foundation

A/c No: 40039624

Sort code: 20-39-07

IBAN: GB84 BARC 2039 0740 0396 24

Swift code: BARCGB22

Gift Aid forms can be downloaded from the website: environmentalmedicinefoundation.org and emailed.

Your support will help us to help fund treatment for more patients in need



(CONTINUED FROM PAGE 1)

My life-changing diagnosis of Ehlers-Danlos Syndrome



Georgie Windsor is on YouTube, Instagram, Facebook, Twitter and has blog posts on Themighty.com Social media: @georgiewinds

managed to just about get by, but I always looked to my friends and wondered why they could walk further, stay out later, and were not always in chronic pain.

Since I was about seven years old, I have visited a lot of doctors, who were mostly dismissive of my symptoms. Blood tests revealed sporadic anemia (low red blood cell count), systemic inflammation, and a lymphocyte count that was chronically low, but no explanation for this could be offered. (Lymphocytes are white blood cells that are also one of the body's main types of immune cells.) A gastrointestinal specialist diagnosed me with irritable bowel syndrome (IBS) and recommended a low FODMAP diet, which involves lowering intake of certain sugars that may cause intestinal distress, but this did not help my symptoms at all. Other than that, my symptoms remained a mystery and only continued to get worse over time.

At the age of 20, I had a huge health crash, which left me bedbound and unable to mentally process the world around me, shower or complete daily tasks unassisted. Upon standing, or even sitting, my heart rate spiked to over 200 beats per minute. I could not keep food down and I was reacting to all but about five foods.

After eating, my tongue would swell and my blood pressure would drop, which would cause me to pass out. My fatigue and pain levels were dreadful, and my joints started dislocating. Furthermore, I woke up every day with a severe headache, swollen lymph nodes and 'viral' symptoms.

I remember my 21st birthday as one of the most miserable moments of my life. Too exhausted and unwell to even interact with my family, I spent it alone in a dark room, wondering if I would ever get better. I felt truly hopeless and that my illness had taken my entire life away from me. I could not work, study, read, walk, or do any of the things I would usually enjoy. I could not even connect with the people I loved because the cognitive strain of doing that would be too exhausting.

At this point, I had no proper diagnosis other than the loose titles of IBS, migraine and then Functional Neurological Disorder (FND). I was left without an answer that accurately explained all my symptoms and was prescribed psychotherapy and physiotherapy.

The mental health side of my illness had become difficult to manage, as I did not feel I was being believed and was experiencing doubt, but also outright neglect at the hands of several doctors. I began to question my own experience, despite the debilitating array of symptoms I was suffering.

Soon after turning 21, I visited Breakspear Medical for the first time. My father found the clinic online while researching a possible Lyme disease connection to my illness. My parents practically carried me in and I do not even remember much of my first meeting with Dr Nikita White. However, within 20 minutes, she changed my life forever. Finally, we began to understand my illness.

I was diagnosed with Ehlers-Danlos Syndrome (EDS), a genetic connective tissue disorder. Additionally, my tests revealed nutritional deficiencies and gut problems, including an infection and candida overgrowth, and ME/CFS. I

(CONTINUED ON PAGE 11)

(CONTINUED FROM PAGE 10)

also had multiple sensitivities to foods, medications, additives, food colourants and chemicals. I had several ongoing viral infections, which had to be treated twice with antiviral therapy. It was also recommended that I see a cardiologist, who later diagnosed me with postural tachycardia syndrome (PoTS), which affects my heart rate and nervous system after sitting up or standing. Together, these diagnoses explained my symptoms.

Pursuing private treatment was a huge decision for my family. Growing up with a national health service, I felt guilty with the expense in the beginning, particularly after being told by so many doctors that visiting a private clinic was pointless and a potentially dangerous pursuit. If only I had known how much the expertise, knowledge and care would transform my life.

I began low-dose immunotherapy to address my sensitivities and targeted nutritional treatment, including infusions and supplementation. It took a while for my body to begin healing, as there was a lot to target, but gradually, I regained my health. Along the way, I passed the milestones of being able again to enjoy reading, to walk unassisted, to stay awake for longer than a few hours, and to reintroduce more and more foods into my diet.

The knowledge I gained at Breakspear Medical not only transformed my life, it also changed the lives of loved ones around me. After my diagnosis, it turned out that many of my family members also had EDS, after years of struggling with unexplained symptoms.

I am now studying at Cambridge University, specialising in Human Evolutionary Genetics, Health and Disease. For me, getting to Cambridge was a dream come true. And thanks to Breakspear Medical, I have been able to pursue my degree and I hope to change the world one day by pursuing research into epigenetics (the study of how your behavior and environment can cause changes that affect the way your genes work) and environmental illness.

Nearly two years after first visiting Breakspear Medical, I still have a few symptoms, I am in almost full remission from my ME/CFS, PoTS, and my allergy-related illness is now mild compared to before. I am very functional and pursue the things I love, which at one time, I never thought would be possible again.

The truth is that without the help of the fantastic Breakspear Medical team and their expertise, I do not know where I'd be. I am forever grateful for their help.



EHLERS-DANLOS SYNDROME

(EDS)

Ehlers-Danlos syndrome (EDS) are a group of rare inherited conditions that affect connective tissue.

There are several types of EDS that may share some symptoms.

These include:

- an increased range of joint movement (joint hypermobility)
- stretchy skin
- fragile skin that breaks or bruises easily

EDS can affect people in different ways. For some, the condition is relatively mild, while for others their symptoms can be disabling.

ME/CFS sufferers may be working harder at rest

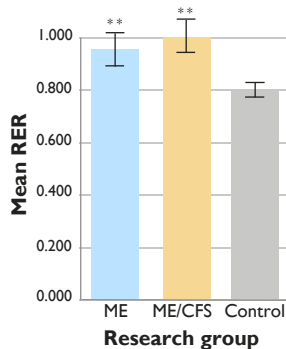
Breakspear Medical patient and university graduate, George Hines, wrote his MSc thesis on a small study that showed that ME/CFS sufferers are working harder at a state of rest than healthy people, which may help explain the fatigue associated with ME/CFS.

Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are often used interchangeably, although some literature argues they are different conditions.

Both conditions share the symptoms of pain, fatigue and neurocognitive dysfunction. For the purpose of this study, the 16 participants were divided into a CFS group and an ME/CFS group.

The Respiratory Exchange Ratio (RER) is a physiological measure used to determine physical effort. It is the ratio between the amount of carbon dioxide (CO₂) produced by the body and oxygen consumed.

To read George's thesis, please visit: www.breakspearmedical.com/georgehines



For both groups in this small study, the RER was found to be significantly elevated when compared to known historical healthy controls (HHC). This indicates that their bodies are working harder than healthy people, even at rest.

The main limitation of this study was the small sample size.



ABOUT THE AUTHOR

George Hines recently finished his Postgraduate Master's in Clinical Research at Norwich Medical School from the University of East Anglia. At the age of 15, George was diagnosed with glandular fever and then seven months later, he was diagnosed with ME. Because of his experience and learning that there was no standard treatment, he became interested in science. Ten years later, he was able to complete this study as his master's thesis.



Have you had a lateral flow test?

From 3 May 2021, as part of our processes to reduce the risk of spreading COVID-19, we are requesting all visitors & staff to take rapid lateral flow tests. Do not use a lateral flow test if you have Covid symptoms; if you have symptoms, get a PCR test and self-isolate. **See page 6 for more information.**

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