



HIGHLIGHTS

Day in the life of our Quality Manager

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It turned her life around Laura Cook's ME/CFS recovery story

Soon to be returning to work after maternity leave, special needs teacher, wife and mother, Laura Cook, shares her personal story of recovery from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to give comfort and hope to others.

My name is Laura Cook. I am 29 years old, married and have two adorable children aged three years and seven months.

Whilst at the moment I am tremendously enjoying maternity leave, I am due to go back to work in early December 2016. I teach children who have moderate and severe learning difficulties in a special needs school.

As I write this now, I can honestly say that ME/CFS is a distant, but

still rather painful, memory.

I was diagnosed with ME/CFS shortly after my marriage in 2009. However, I had been suffering for sometime before then. I had recurring bouts of glandular fever and a very low immune system. Throughout university I was always the first to fall ill. It became a family joke that I had every '-itis' possible: tonsillitis, laryngitis... You name it and I was coming down with it.

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Day in the life of our... Quality Manager Angeline Cottrill

My workdays start at 9am with a read through my schedule for the day. Because my role is very diverse, no two days are ever alike.

My responsibilities include non-clinical patient care, as well as legal and compliance regulatory checks laid out by the Care Quality Commission (CQC), Department of Health (DOH) and other medical practice regulatory bodies.

One of my favourite tasks is to attend the weekly doctors' journal club. This is where our doctors share and discuss new medical research papers and developments and apply the latest findings to our patient care programmes accordingly. I find these meetings absolutely fascinating, as I am not medically trained and have learned so much!

Before coming to Breakspear Medical, I had over 20 years' experience in Customer Care. To me, it is imperative that our communication with patients is clear and structured and I aim to make any necessary adjustments to ensure that we are doing the very best we can. So this is the perfect opportunity for me to ask you to take a moment to complete one of our patient satisfaction surveys! I read every one of them, as they are instrumental in improving our services. I am also very keen on speaking to people face to face, if preferred.

As well, I believe that good communication between our staff is paramount so I hold regular meetings with department heads and doctors, to ensure we are all working in unison.

I can very much relate to the feelings experienced by many of our patients. I believe this gives me an understanding of their journeys and of how difficult it can be to cope with chronic illness.

I myself have recovered from ME/CFS

Remembering back to when I started developing ME/CFS, I fell ill whilst training for the Brighton Marathon and assumed I had the flu. I had been a fit, strong runner and the illness took away my ability to walk and even think on some days. At that time, I couldn't imagine ever feeling well again.

I am now thankfully pretty much back to normal and am able to participate in sport again. On 2 October this year, I completed my first triathlon and am back up to running half marathon distance, which are activities that I'd previously believed I would never be able to do again. I am determined to run an ultra-marathon one day and compete in more triathlons. I love the camaraderie of sport and really enjoy collecting the medals!

My favourite part of my role is meeting patients and having the opportunity to enhance their experience at Breakspear Medical. It is so heart-warming to see patients improve or recover after their treatment. I love working here, particularly because of the holistic medical approach and the passion and dedication of the team to make sure that our patients' care is at the heart of everything we do.



Hope & victory: video interview with Colonel Carlo Calcagni on overcoming MCS

After winning three gold medals at the 2016 Invictus Games, Italian paracyclist Col Carlo Calcagni shares his story in an interview in order to give other multiple chemical sensitivity sufferers hope.

Between training for the 2016 Paralympic qualifiers and receiving treatment at Breakspear Medical, Col Carlo Calcagni sat down in front of a camera crew to tell his story of how he was exposed to harmful chemicals while serving in the Italian air force and how his health deteriorated drastically in the months thereafter.

In the video interview, currently available on Breakspear Medical's YouTube channel, he states, "It was very hard to accept such a brutal and unexpected knock... I was a top sportsman, always careful of what I was eating and of my habits. I was living an athlete's life!"

His interview is personal and inspiring. He speaks in his native Italian, with English subtitles displayed and many images from important events of his life.

The video had over 700 views in its first week on air.

Many of his supporters on social media who have watched the video have commented that it brought them to tears. One supporter wrote, "Beautiful video. It passes the perfect message of what you are."

The reason he shares his story is to give hope. He came back to become a sportsman again and, with support in managing his condition, has been able to demonstrate to other people who are ill that it is possible to keep going even with health issues.

Watch Col Carlo Calcagni's full video interview on our YouTube channel:
<https://youtu.be/e-akx0cnOWQ>



Lecture outline:

Talking about autoimmunity & Lyme

As part of the 2016 Breakspear Medical and the Environmental Medicine Foundation lecture series, newly appointed European Chairman of ILADS, Dr Pol De Saedeleer, presented on auto-immunity and Lyme disease.

Presenting his lecture *Induction of autoimmunity*, Dr Pol De Saedeleer started with the surprising statement, “Less than 10% of all Lyme cases are officially diagnosed and reported.”

Dr De Saedeleer has a particular interest in Lyme disease and has given seminars all over the world on this topic, including at the International Lyme and Associated Diseases Society (ILADS) and the American Academy of Anti-Aging (A4M). He explained that there are many challenges in diagnosing

Lyme. The biggest challenges are that the symptoms differ considerably between patients, which is because they are presenting with different infections and have different strains of the infecting microorganisms that cause the disease (called pathogens), and this is further complicated by symptoms of co-infections (other infections that are happening at the same time). The symptoms of Lyme can mimic many other diseases, including arthritis, lupus,

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EXAMPLES OF AUTOIMMUNE DISEASES:

- coeliac disease
- diabetes mellitus type 1
- systemic lupus erythematosus (SLE)
- Sjögren's syndrome
- Hashimoto's thyroiditis
- Graves' disease
- rheumatoid arthritis (RA)

Visit Breakspear Medical's YouTube channel to view the entire lecture with notes.

Talking about autoimmunity & Lyme

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multiple sclerosis and thyroid disorders.

A doctor trying to diagnose and treat the patient's symptoms must then choose and evaluate the right laboratory analyses. While it would be ideal to be able to run every test available, due to associated costs and, in some cases, restrictive treatment guidelines, many doctors are not able to run a wide range of tests in order to best narrow down the cause(s) of the patient's symptoms.

Lyme is a multi-infectious disease. This means that once the pathogen *Borrelia* has infected the body, other different pathogens, such as *Babesia*, can be more easily contracted causing other disease(s) and/or earlier infection(s) to be reactivated. This results in Lyme infection and co-infections, to present a myriad of symptoms from each.

A study published in 2000 indicated that 38.5% of patients diagnosed with multiple sclerosis (MS) had a

positive serologic reaction to *Borrelia* (the pathogen causing Lyme). The positive serologic reaction shows that these patients' immune systems have, at some point or another, had to defend the body against *Borrelia*.

With so many symptoms appearing in patients, some overlapping and others entirely separate, it is easy to understand why many cases of Lyme go undiagnosed, with some patients being diagnosed with the co-infections and others not receiving a diagnosis.

Lyme is a multifactorial disease. With Lyme, immunity is disturbed, inflammation occurs, hormonal imbalance can happen, as well as brain function impairment and disruption to the detoxification system, causing toxins to accumulate.

To successfully treat Lyme, extensive testing is required, to determine all risk factors and address the multifactorial symptoms.

ABOUT AUTO-IMMUNITY

- Autoimmunity is the system of immune responses of an organism against its own healthy cells and tissues.
- Autoimmune processes are very complicated and include many different disease processes.
- A mechanism by which infection is linked to auto-immunity is molecular mimicry.
- Molecular mimicry is when the organism's own protein resembles a foreign invader, which activates the immune system against its own protein.



We'd like to hear about your recent experience at Breakspear Medical.

We would be grateful if you would complete our *Patient satisfaction survey* in order to help us improve our service to you in the future. The survey shouldn't take more than ten minutes to complete. Copies are available to pick up and drop off in the Patient Dining Room.



Is it ME, CFS, PVFS, CFIDS or SEID?

Persistent fatigue (exhaustion) that does not go away with rest and, over time, leads to a compromised quality of life, long-term illnesses and disability, is estimated to affect around 250,000 people in the UK.*

There is ongoing debate over the best term to use to describe the debilitating long-term fatigue condition.

The term chronic fatigue syndrome (CFS) emerged from the USA in the 1980s to describe fatigue that lasted for more than six months. However, from the start, many healthcare professionals did not believe that it was a medical illness and believed that it could be treated with cognitive behavioural therapy and/or exercise.

The terms myalgic encephalomyelitis and myalgic encephalopathy (both known as ME) are also used to describe a chronic fatigue state. The prefix “encephalo” means ‘of the brain’. Since 1969, the World Health Organization (WHO) has classified ME as a specific neurological disorder.

For many years, the terms CFS and ME have been used nearly interchangeably by the medical profession, although some would say that CFS evolved into a further-reaching disease designation and encompassed ME.

Other terms include chronic fatigue immune dysfunction syndrome (CFIDS) and post-viral fatigue syndrome (PVFS). The term systemic exertion intolerance disease (SEID) evolved, free from the stigma attached to the term CFS, and is more encompassing than the term ME. However, the term has not gained global recognition to date.

At this time, Breakspear Medical has chosen to use the term ME/CFS to refer to cases of persistent fatigue and will continue to treat such cases on an individual basis.

* Taken from www.nhs.uk/conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx [2016 Oct 13]



Please help us
help more

Environmental Medicine
Foundation

Registered charity: 1100205
www.environmentalmedicinefoundation.org.uk

Thank you for responding to our previous appeal!

We are hoping to raise some extra money for the coming year to enable us to undertake further activities which we consider to be essential, such as education, research, and funding patients in need of financial assistance.

At present we are working in conjunction with Breakspear Medical on one of the Foundation's main objectives, which is a programme to increase awareness of environmental illness and what can be done about it.

You can help support the EMF by attending our seminars about environmental illness, its causes and the effective treatments, or by donating directly to the charity to help fund treatment of patients who need help with the costs.

**We wish you the best
for Christmas & the New Year!**

Environmental Medicine Foundation

Registered charity: 1100205
www.environmentalmedicinefoundation.org.uk

Maple House, Wood Lane
Paradise Industrial Estate
Hemel Hempstead, Herts
United Kingdom
HP2 4TL

If you would like to support the Environmental Medicine Foundation,
please complete the following form and post to the address above.

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Swift code: BARCGB22

- ☐ Credit/debit

If you wish to make a donation by credit/debit card, please call
Breakspear Medical's Accounts Department 01442 261 333 ext 297 to
pay securely over the phone.

Please note: we do not accept American Express.

Thank you in advance for your support!

RECOMMENDED RECIPE:

Apricot amaretti slices

A gluten-, dairy-, and sugar-free biscuit



INGREDIENTS:

300g ground almonds	4 eggs
200g xylitol	1 tin apricots (in unsweetened juice)
100g cornflour	3 good handfuls of flaked almonds
2 tsp almond extract	

METHOD:

1. Preheat oven to 180°C/Gas mark 4.
2. Prepare a 25cm x 17cm baking tray by lining with greaseproof paper.
3. Drain the apricots, halve them and set aside.
4. Mix the ground almonds, xylitol, cornflour, eggs and almond extract until smooth.
5. Spoon onto the lined baking tray and smooth out until about 2 - 3cm thick.
6. Lightly press the apricot halves, evenly spaced apart, into the base.
7. Sprinkle the flaked almonds on top.
8. Bake for 20 - 25 minutes, until the top is light golden colour.
9. Cool and cut into approximately 12 slices.

COOK'S NOTES:

The tinned apricots can be substituted with fresh or soft apricots, cherries in season or tinned or fresh plums.

Dr Jean Monro presents at 2016 Environmental Sensitivities Symposium



The research papers presented

at the ESS were compiled into a textbook, which can be purchased online:

ecohealthsolutions.com.au/ess/textbook/ with 100% of the profits from the sale of the books to be donated to environmental sensitivity-related charities.

In October 2016, Breakspear Medical's Dr Jean Monro was interviewed about her paper entitled, *The effects of dietary intervention on the behaviour of deaf school children*, which looked at the successful changes to school children's diets to improve their behaviour and health.

Her interview was part of the online 2016 Environmental Sensitivities Symposium (ESS), which was held 17-22 October 2016.

The symposium's organiser, Australian Building Biologist Lucinda Curran, brought together a series of recorded

lectures by 15 global experts in the field of environmental sensitivities. The experts were then interviewed live online about their submitted research paper.

The topics vary from chemicals, obesogens, citizen science, clinical assessment of environmental sensitivities, and how to identify and deal with the hidden hazards in the home.

Dr Cyril W Smith, who has been helping chemical and electrically sensitive patients since the 1980s and has written several books on the topic, presented his paper, *Hertz and Hurts*.

ILADS conference attended by Dr Cyprel Ijeh

The International Lyme and Associated Diseases Society (ILADS), which is a global leader in Lyme disease education and training, held its annual Lyme scientific session 4-6 November 2016 in Philadelphia, USA

In order to give doctors and researchers the tools to diagnose and treat tick-borne diseases, ILADS holds an annual conference to foster collaboration and dialogue between Lyme disease researchers and those who care and advocate for Lyme disease patients in a variety of settings.

Dr Cyprel Ijeh attended the conference

and submitted a poster, which illustrated findings at Breakspear Medical.* The poster explained that in the sample group of people studied, there were no adverse effects of intravenous ceftriaxone (an antibiotic) on the liver when two key nutritional supplements were taken during treatment.

* Puri BK, Hakkarainen-Smith JS, Derham A, Monro JA. Co-administration of α -lipoic acid and glutathione is associated with no significant changes in serum bilirubin, alkaline phosphatase or γ -glutamyltranspeptidase levels during the treatment of neuroborreliosis with intravenous ceftriaxone. J Complement Integr Med. 2015;12:227-30.



Ongoing open lectures

Organisation is underway of a series of diverse lectures throughout 2017 for patients, healthcare professionals and anyone interested in environmental medicine.

Breakspear Medical and the Environmental Medicine Foundation presented the third of the 2016 open lectures series on Friday 14 October, called *Pathogens inducing autoimmunity*.

Visiting guest speaker Dr Pol De Saedeleer, European Chairman of ILADS, presented his lecture *Pathogens inducing autoimmunity*. (See brief summary on page 4.)

Breakspear Medical's Specialist in Infectious Diseases, Dr Daud Mohamed, presented *Treatment of Lyme persisters*.

The lectures were recorded and are available on Breakspear Medical's YouTube channel.

Dr Jean Monro is currently recording her explanations of various key terms and conditions related to environmental medicine, which are to be uploaded to the YouTube channel. The release dates will be announced on Facebook and Twitter.

Information about upcoming lectures will be available on our website: breakspearmedical.com/resources and announcements are made on Facebook and Twitter. Tickets will be available from eventbrite.co.uk

Follow us on Facebook or Twitter to receive updates.



Laura Cook's ME/CFS recovery story

(CONTINUED FROM PAGE 1)



I was diagnosed with severe CFS by my family doctor. Whilst he was supportive, I was offered little practical help. I was prescribed antidepressants and little was done to explain to me what the condition was. I quickly found out that little was actually known about it. After a lot of visits to the surgery, all of which were a huge effort, it was my father who actually came into a consultation and pushed for a referral, saying "There must be someone who fully understands the situation we are in." We were referred to St. Bart's in London. The train journey and then the taxi ride really took every ounce of energy I had. We met with a doctor who informed us that the ward that dealt with fatigue patients had been closed down. He said he would write to my doctor suggesting Cognitive Behavioural Therapy. I left St. Bart's totally and utterly lost.

The condition had impacted my life in just about every way possible. As a newly qualified teacher, my first year in the profession was incredibly tough. I worked 50+ hour weeks in addition to having a lengthy commute, which I literally dragged myself through. Reflecting on this time it is clear now that I 'lived to work', and not 'worked to live'! I had a constant fear of letting people down, especially my pupils, specifically those due to take exams.

I would leave the house at 7:00am and return at 6:00pm. By this time, I was too exhausted to cook and many nights passed with me sitting in the dark, unable to muster the energy to draw

the curtains or even to turn the living room light on. I had to cancel so many social engagements because I simply did not have the energy to get ready, travel or even hold a conversation. Despite all of this, to an outsider, it looked like I was coping. Living like this became normal for me and I became very accomplished at hiding my illness and ploughing through.

I felt as though my condition was invisible to others. I was excelling in my career, had good relationships, and was immaculately turned out. On the surface, I looked healthy and happy. However, periodically I would crash; either I would increase my workload and my body would effectively say "enough is enough!" or a relatively minor illness, such as a cold, would completely wipe me out.

These periods of illness were the hardest and I suffered some very black thoughts. At times, I was unable to get out of bed. I struggled enormously to feed and care for myself, my arms ached and weighed so heavily I could hardly lift them. Alongside this, I had shortness of breath and trouble sleeping, which made me very tearful. Simple, everyday tasks were impossible.

I like to think of myself as a fairly intelligent individual; what I found hardest to cope with was what I called brain fog. I would be unable to hold a conversation without getting my words muddled. I struggled enormously to make simple decisions; a cup of tea or coffee seemed like a great dilemma. I was trapped in my own body.

During this time, my family and friends were fantastic and I will be forever grateful for the care and understanding they showed me. Without them, there is no way I would have made it through. I strongly believe the fact they remained positive when there was so little hope helped me recover. The darkest of clouds

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always had a silver lining.

It was in May 2012 when, rather amusingly, a Google search by my not-so-tech-savvy grandmother led us to Breakspear Medical. At this point in my illness, things really could not have got any worse. I was on long term sick leave from work, in enormous amounts of pain and incredibly low. Fatigue had engulfed my very being. As a newly married, young woman my quality of life was very poor. Breakspear Medical really felt like our last hope.

I will never forget our initial consultation. I could barely walk into the consultation room, as every movement was slow and painful. I literally had nothing left. I was far too weak and unwell to see Dr Jean Monro on my own. I could not talk or formulate my thoughts. My husband and mother outlined my condition and spoke for me. As my mother reflects back on this time now, she says I was in total despair. Having been married for three years, my husband and I wanted children but we were told that my body was too weak to carry a child. That news was devastating. Thank goodness we were offered some hope by Dr Monro who felt she could improve my condition and make me better. We clung on to this. At last we felt someone understood.

After a plethora of tests, my treatment at the clinic started in late July 2012 and ended in early September 2012. I was sometimes at the clinic six days a week. The care I was given was exceptional. There were times I lay in bed in tears because I felt like my body just could not take anymore. At my lowest points, the nurses offered hope. I underwent food intolerance testing, low-dose immunotherapy, and was given almost daily IV infusions as well as antiviral medication, IRATHERM® treatment and many, many supplements to take.

I followed Dr Monro's recommendations to the letter. My diet was drastically changed and I followed this incredibly strictly. And slowly I began to improve.

Four years ago, I was too weak to leave my home, I could not care for myself or hold a conversation.

At the beginning of my treatment, I lay in a bed without a scrap of makeup and as things progressed, I moved to a chair and began to take pride in my appearance again, and towards the end of my treatment plan, I was walking in wearing towering wedges with a full face of makeup. I was becoming me again.

Leaving the clinic after my intensive treatment felt like a victory, as a family we had done it! We were so thankful.

Prior to this illness, I had been one of these irritatingly fortunate people that had everything fall into their lap, education, career, friends, family; but I had taken my health for granted; never again.

Looking back now it seems nothing short of crazy to have begun trying for a baby immediately but my husband and I desperately wanted to start a family. I fell pregnant with Emily in February 2013 and I was incredibly lucky to have a textbook pregnancy. Our beautiful little girl was born in October 2013. Finishing treatment at Breakspear Medical was by no means the end of the journey. Even after my health returned, the psychological impact of it all remained. I was petrified of becoming ill again despite knowing I was looking after myself in the best possible way I could. My parents suggested Cognitive Behavioural Therapy and despite the therapist not actually saying anything different to my family and friends, this helped me enormously.

Four years ago, I was too weak to leave my home, I could not care for myself or hold a conversation. Recently I ran thirteen miles in 2 hours 52 minutes, participating in the Great North Run. Today I am enjoying married life, have two fantastic children, a successful career and am training for my first marathon.

From the very bottom of my heart, I hope that this story offers some comfort and hope to those going through the same or a similar illness. Never let the stumble be the end of your journey, wishing you all luck and the very best.

2016 CQC report published



The CQC (Care Quality Commission) is the independent regulator of health and social care in the UK.

On 5 April 2016, the CQC inspectors visited Breakspear Medical to conduct a routine inspection and on 1 August 2016 their report was published, which showed that Breakspear Medical met all the requirements.

The CQC's current strategy for inspections is to ask five key questions about the facilities being inspected to form the framework of areas looked at during an inspection. These key questions are:

- Are they safe?
- Are they effective?
- Are they caring?
- Are they well led?
- Are they responsive to people's needs?

The inspectors recounted, "We found a friendly calm and optimistic atmosphere at the service during our inspection. We saw that members of staff were very helpful and polite to patients and treated them with dignity and respect. People who used the service told us they felt well cared for by staff members that were kind, professional and highly knowledgeable..."

The full report is available online: cqc.org.uk

PROFILE...

Dr John Mansfield 1936-2016

Considered to be one of the fathers of ecological medicine in the UK, Dr John Mansfield recently passed away at his home in Cyprus.

Dr Mansfield gained his medical degree at Guy's Hospital, London and focused on ecological medicine from 1976 onwards.

He founded the Burghwood Clinic, in Surrey, treating patients with inflammatory conditions using dietary changes and treating allergies and hypersensitivities, which were often the root of inflammatory disease.

In 1978, he became a founding member of the British Society for Allergy & Environmental Medicine, now known as the British Society for Ecological Medicine.

He had several books published, including *The migraine revolution* (1986), *Arthritis: the allergy connection* (1990) and *The asthma epidemic* (1997).

Published by



Breakspear Medical Group Ltd
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Hertfordshire HP2 4FD United Kingdom

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Breakspear Medical Bulletin is a private publication that we aim to produce twice annually. It is for the promotion of environmental medicine awareness and Breakspear Medical Group Ltd. This newsletter is not intended as advice on specific cases but as a forum of information researched and stored at Breakspear Medical Group. We urge readers to discuss the articles in this bulletin with their health-care practitioners. Unauthorised reproduction of this newsletter, or quotation except for comment or review, is illegal and punishable by law.

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