

tions, giving disease and PSA control for many years. Many of the treatments now being offered at St. Richard's and Guildford were available only at the Royal Marsden 10 or so years ago. Now, thanks to the Movember fund-raising, much better treatments are available and really make a difference.

Mr. Hicks said that "One of the 'ugly' parts is how I spend the funds to do the best for any particular patient. 1410 men need to have PSA screening, with a further 48 receiving treatment for aggressive cancer to prevent one dying from prostate cancer. A research programme is needed to find a better test than the current one and then those figures will change. However, 75% with a raised PSA do not have their lives threatened, the challenge is to find the 25% where it will shorten life. If you are over 60 and have a reading of less than 1, you probably don't need it checked for several years if you are fit and active; if the result is borderline, then a repeat might be indicated in a year, but in asking for a test (which any doctor ought to allow if you are over 50), you need to understand what it means – if there are any risks. If the result is normal, would you be reassured, if high, what would you do, and if diagnosed with a type that probably would not cause a problem, would you want treatment with possible side effects? Important factors are your weight, cancer, diabetes, heart disease and your family history as described earlier."

Summing up, therefore:
The 'good' is the number of options available which are tailor-made to each patient – but the need is to see the patient earlier (70s and 80s too late)

The 'bad' is that the MRI is 'not quite there yet', but is less invasive as it avoids needles

The 'ugly' is a biopsy, although most don't need a general anaesthetic and are day cases; they are gentle and easy and 'over-egged' as they are very manageable. The other 'ugly' part is the 2-week rule if there is a suspected cancer, leading into the 62 day rule when you are fast-tracked into an important decision.

A question about proton beam treatment told us of the vast cost to the tax payer (£150m) with "no evidence that it works compared with conventional beam radiotherapy, although it is particularly good for brain tumours".

Dr Fooks passed on the question from many of his patients about sexual function – the answer to which is that everything has side effects when trying to cure a cancer, but the good news is that most don't need "a heavy duty mallet", most are well tolerated and that sexual function will be much the same as before any treatment.

Mr. Hicks was asked how good the PSA test is, to which he replied that "the reading fluctuates small amounts all the time and is influenced by such things as infection, inflammation, riding a bike and sexual intercourse, but the higher the PSA the higher the risk based on statistical chance, with the cause of cell production being 'the Friday afternoon cell' which by the late 60s will have accumulated a few things that aren't quite right, so it is not due to one individual factor; 70% of over 80 year-olds will have a degree of cancer which is not smoking-related but due to genetics".

Hormonal treatment (such as finasteride or dutasteride) can be prescribed to shrink an enlarged prostate to help with flow and night time peeing, but it will be back to the enlarged size after 6-9 months if you stop taking it. Immunotherapy – within a decade – will allow the immune system to treat cancer, so removing the need for surgery and radiotherapy.

Mr. Hicks closed by stressing the vital importance of support from family and friends during treatment, and this was enforced by David Hurst of the local prostate support group.

Very many thanks to Mr. Hicks for his very well presented information on a subject which a few years ago would not have been mentioned, and also to the two members of the audience who shared their experiences, reinforcing Mr. Hicks' statement that, although treatment is not something anyone looks forward to, it is not as bad as many fear.



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DATES FOR YOUR DIARY 2020
Our Public Meetings next year are scheduled for the 1st Monday in March, June and October in Pulborough Village Hall
7.00 pm Talk – approx. 8.30 pm
Refreshments and Raffle Draw

ME/CFS (MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME)
A patient's journey

I had ME for 22 years – and that "had" should really be in glowing italics, for I can hardly believe I am now able to use the past tense.

ME – or Chronic Fatigue Syndrome – is an odd illness. Few agree on either its causes or its treatment, and it can affect children and adults of any age. Some end up bed-ridden or in wheelchairs; others less badly afflicted, like me, cope reluctantly in a yo-yo state of feeling comparatively OK one day then scarcely able to function the next. A trip to the supermarket can wear you out. A common danger signal is feeling unnaturally energetic and able to conquer the world: you do too much and later collapse in an exhausted, tearful mess. You must pace yourself, or face the payback.

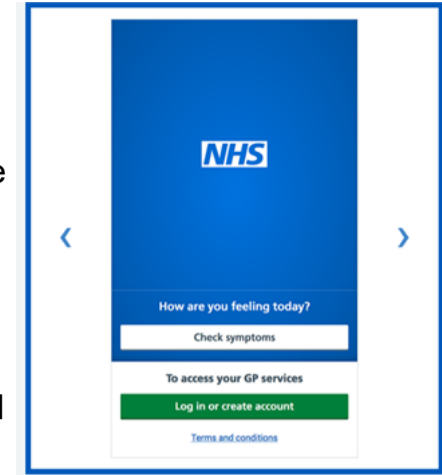
ME tiredness is not the kind you feel after normal exertion or a late night, but a deep, desperate, drawing-down tiredness that stops you in your tracks. It can bring with it brain fog, muscle aches (fibromyalgia), light sensitivity, and a whole lot else. In my case, it often came with a high temperature, sore throat and swollen glands, forcing me into bed for at least two weeks at a time. Before the original clinical diagnosis, I'd been tested for a long list of possible underlying disorders, all to no avail. There seemed no other option than resigning myself to the status quo.

For many years I rested all afternoon in order to get through the remainder of the day. But because I could

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- register to be an organ donor – easily manage your preferences on the NHS Organ Donor Register
- choose how the NHS uses your data – register your decision on whether it can be used for research and planning



To create an account and to log in, you will need to know Pulborough Medical Group's practice ODS code which is **H82030**

Get the NHS app

To get the NHS App, you can download it from either the Google Play or Apple app store.



Further information

<https://www.nhs.uk/using-the-nhs/nhs-services/the-nhs-app/>

There is also a very useful YouTube video showing Dr Hussain Ghandi of eGPLearning taking you through step by step on how to register.

https://www.youtube.com/watch?v=4nRhmJ_tll4

or search on YouTube for 'NHS App' and select 'How to register with the NHS App'

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then act normally, I was loath to admit to anybody outside a small close circle exactly what was happening and how often I "crashed". I didn't want to join support groups, I didn't want to be defined as a "sufferer", and I didn't want my husband and myself crossed off everybody's guest list: your nearest and dearest are also affected by this capricious condition that is almost impossible to explain or understand. I also suspected that, as a freelancer, I would find that work dried up if I was deemed potentially unreliable.

So, rightly or wrongly, I operated on a need-to-know basis, lied like a trooper to conceal the situation and beavered away in the background with a raft of possible "cures": weird diets, graduated exercise plans, concoctions of Chinese herbs that stank the kitchen out - you name it. Cognitive Behavioural Therapy, kindly organized by my GP, was the most helpful as it identified triggers and patterns of fatigue. Through it, I was able to reduce the long afternoon rest to a much shorter one before lunch, ie top up the batteries before they run out. That was a welcome change, if difficult to organize away from home as resting effectively seemed only to work if I was quiet and horizontal. I prefer to forget the day I once headed for the bed department of a large store and stretched out, only to have salesmen appearing every few minutes to extol the virtues of pocket springs...

I had to accept the near impossibility of planning a demanding holiday, or even a whole day out, and to deal with flare-ups if I broke the cardinal rule of "being careful". Sometimes, I admit, the downs were worth the ups: I wouldn't have missed a certain friend's wedding for anything, nor another friend's special birthday party. Given half a chance, ME can sap the enjoyment of life but it's not a killer; you just have to weigh up consequences. Sadly, we knew people who were succumbing to far more serious illnesses, and it seemed the height of self-indulgence to rail against the restrictions imposed by mine.

We are very grateful to the readers who have suggested topics for future newsletters, these being:

Bereavement, including reassurance, signposts to support, tips on how to ask for help and hints for others on how to talk to bereaved people.

Sleep - tips for a good night's sleep and info on sleeping tablets and aids.

These subjects will be covered in the next couple of issues.

Any other suggestions? Please contact the editor - lae@ianellisassociates.com

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Then eighteen months ago someone – to whom I shall be forever grateful – suggested I try The Lightning Process (LP). Brainchild of English osteopath Phil Parker, it was described as a deceptively simple self-healing technique which, in 20 years, had helped an impressive number of people in several countries to recover from a wide range of conditions; amongst them ME.

Too good to be true, I thought. Yet reading about it online, listening to Phil Parker on YouTube and scanning the opinions of sceptics and enthusiasts, I wasn't so sure. My husband and I went to London to visit the LP headquarters near Victoria Station for one of their free introductory talks.

We were cynically prepared for a hard commercial sell. Instead, a thoughtful lecturer who encouraged questions explained in detail how the LP incorporates ideas drawn from neuro-linguistic programming and life coaching, showing how, in controlled circumstances, you can influence your own physiological responses. Everyone nowadays recognises that the mind can influence the body, and it was tempting to think this could be merely an expensive way to practise bog standard mind-over-matter. However, digging deeper into the science, we could see that there was more to it.

Back home, I watched the videoed testimonials on the website of my local LP practitioner, who herself had ME for many years before being cured by The Lightning Process. After much thought - and scrutiny of my savings account - I applied to go on her next available course.

The first surprise was not being immediately accepted. Practitioners can judge who is likely to get the most out of training, and there was form-filling and a long phone conversation before I was finally told that I had a place if I still wanted it. The course a month hence would be across three half-days (11am – 3pm); in the meantime, plenty of reading matter, podcasts etc could help as preparation.

I worried about getting my pre-lunch rest but Linda, the practitioner, assured me this wouldn't be a problem, and it wasn't. There are comfy sofas in the sitting-room of her home where she works and, as she said, trainees have varying needs, some even arriving on a stretcher. The atmosphere is friendly and informal and to my amazement I was so intrigued by what we were doing that each midday came and went with my barely registering: an intimation of things to come?

There were three of us apprehensive hopefuls, plus the mother of one of them who'd come to observe; her young daughter had lived with severe fibromyalgia pain for months and both were at the end of their tether. Via slides, talks and personal involvement, we were shown how brains and bodies can get "stuck" by responding to challenges in automatic but inappropriate ways and how we could normalise these by using the Process, itself most easily described as a particular combination of movements, self-coaching, and a set of precisely targeted questions. The aim was to build alternative neurological pathways that could then create new, healthy ways of responding.

Initially I'd imagined there might be an element of padding to fill the allotted time but, although there was a re-cap each morning of what had been discussed the day before, sessions were tightly constructed; also good fun, with easy lunch thrown in and ample opportunity to chat. There was optional homework (though I was too shot to do anything but read through the day's summary notes). And by the end all three of us, in theory anyway, had a set of valuable life skills under our belts to confront our current demons and indeed any future ones.

I say "in theory" because those skills needed to be practised regularly in order to become literally second nature. Clever though the LP is, it's no good simply thinking about practising it. You have to *do* it – often and during every single day to begin with, until your brain adjusts. It's slightly like adapting to a new pair of prescription glasses when you gradually find you're seeing the world in a different, better way.

Some people have immediate benefits; the young girl on our course was pain-free and euphoric by the end of it. Others, like the third member of our trio whose chronic disorder I later discovered had begun to show some improvement, are unable to commit to the further work involved and so give up. For yet others, myself included, it can be a stop-start journey. The trick is to persevere and, as importantly, to take advantage of the generous ongoing follow-up and support that is part of the package. When I was floundering a bit on my way to eventual success, I rang Linda for clarification about some aspects of the teaching and she was immensely helpful.

The price of a course varies between practitioners and locations. Mine cost £650 and, considering that it changed my life, was well worth the investment. The Lightning Process may not work for everyone, but all I can say is that it worked for me. I have my energy back, I've been able to give up regular rests completely, and I can now plan life without constraints. Best of all, I'm now able to say I *HAD* ME instead of I *HAVE* it - after 22 years, that's some achievement!

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This patient is very keen to help anyone who has ME and would be happy to talk about issues raised in this article. Contact details sent to lae@janellisassociates.com will be passed on.

Editor

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PROSTATES - THE GOOD, THE BAD AND THE UGLY

Mr James Hicks, Clinical Lead

Urology Multidisciplinary Team, St. Richards and Nuffield Hospitals, Chichester

Our meeting in October to hear Mr James Hicks talk about prostates had a packed hall and his 45-minute presentation was very well received, closing with many questions both publicly and privately.

He began by telling us about the Support Movember poster which shows a man with a curly moustache, this campaign having raised millions all round the world, particularly Australia and New Zealand, for research including men's health, prostate and testicular cancer and mental health.

Mr. Hicks said that the good news is that men are much more likely these days to go to the doctor - and much earlier - to get a diagnosis and "we can only do something about it if we know it is there", adding that where the prostate is - and therefore accessibility to it - "is a very poor design"!

Symptoms of enlarged prostate or prostate cancer include urinary frequency, slow flow, urgency, hesitancy, dribbling, bone pain, blood in urine (which must never be ignored) and general malaise/tiredness.

Risk factors:

- Age – not many in the 30s and 40s, 50s some, with 60s and 70s much more likely
- Family history – if you have a first degree relative (father or brother), or a second degree relative (cousin); it is important to find out whether you are at this higher risk
- Afro-Caribbean

Tests are: a rectal examination (which Mr. Hicks said "is not a highlight of the job", but that is where to examine); a PSA blood test, which is an extremely useful tool to see which risk group you are in – it is a simple test and, although not perfect, is the best there is at the moment; an MRI where the technology is good, producing amazing pictures, the downside being that it takes 30-40 minutes and is noisy and cramped; ultrasound guided biopsy (where needles are inserted through the backside or the perineum which means there is less risk of infection) – linking an MRI scan to the probe makes a biopsy really accurate, the results showing exactly where the cancer is – whether one side or the other, how many pieces, the size and aggressiveness of the cells (whether they will grow quickly or slowly). He added that technology is changing all the time and is very different from 5-6 years ago, however, biopsies will still be needed for the immediate future. If necessary, a scan will show if a cancer has spread to the lymph nodes or the bones. Further tests in the next big revolution are a CT scan and a PET CT scan, looking for spread elsewhere to determine whether there should be radiotherapy or surgery.

Referring to the title of his talk, Mr. Hicks said that one of the 'ugly' sides of the NHS (to meet their targets) is that a patient has 15 minutes to make a decision regarding his options. Tailor-making treatment is very important dependent on age - which would be very different for a 45-year old marathon runner to that of an 85-year old whose general health is not as good. Patient preference is a strong motivator, with a third asking him "to cut the damn thing out", a third saying "no knives" and the remainder having difficulty making up their mind, in which case he would try to help with that decision, taking the size, grade etc. into account and also guiding when a patient tells him that a particular treatment "worked alright for a friend of his". Possible courses of action include surgery, active surveillance – accepting that it is mild and unlikely to affect the patient over many years without "chopping, poisoning with drugs or frying with radiotherapy" and would be a "cancer they die *with* rather than *from*". This means not ignoring the problem but actively looking for PSA readings rising, offering appointments, MRIs or repeat biopsies.

"How can I help myself?" Looking at the Prostate Cancer UK website is a useful starting point, with focusing on a healthy diet being important, not only for prostates but also bowel, blood pressure - and general health. Of particular value are lycopenes, carotenoids, vitamin D, super berries - blueberries and pomegranates - oily fish, soya products and green tea, in other words a diet like Jamie Oliver's Mediterranean diet is recommended.

If surgery is the option agreed upon, there are three ways – 'open', laparoscopic (keyhole) and robot assisted laparoscopic (where the surgeon guides the robot with the use of a big TV screen; however, these machines cost between £1.8 and £2 million).

Technology is changing at a spectacular rate with the imaging revolution being extraordinary, allowing radiotherapy to be much more precise, specific and targeted. Radiotherapy can shine a beam from the outside, with brachytherapy allowing for the accurate placing of 'seeds' into the prostate which will deliver radiotherapy to the whole prostate for several months.

All of these choices are good ones as they mean less trauma, are reliable, state of the art and are not likely to go wrong.

High intensity focused ultrasound (HIFU) is minimally invasive using a probe which heats, killing the cancer cells and which is not felt afterwards, the downside being that it can heat the bowel also.


The final option is hormonal treatment which "turns off the fuel" that makes the cancer cells grow and is a combination of tablets and injection.



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