Keeping Well?

The Newsletter of the Nuffield Patient Group

Summer 2017 Issue 17

Welcome!

Hope you've been able to stay cool in this lovely summer weather. "Slip, slap, slop" was what I was taught in Australia: slip on a shirt, slap on a hat and slop on the sun cream, and keep out of that fierce sun in the middle of the day. It isn't any good for anyone, let alone the mad dogs and Englishmen in Noel Coward's song.

We have another great issue for you, with quite an emphasis on feeling well as well on as keeping well.

- Elizabeth Kinder completes her two-part article on coming to terms with MS (this page).
- We explore the importance of the active steps everyone can take to feel better, whatever their physical state (page 3).
- Our cartoonist Tim is back on page 4.
- News from the Practice is on page 4.
- We have all the dates for activities in Witney for those with memory loss: lots of good local stuff for patients and carers (page 5).
- Finally, Sarah from the Cochrane Collaboration explores what the evidence says about which rub-on creams and gels work best to relieve pain (page 6).

A patient story: living with MS

By Elizabeth Kinder

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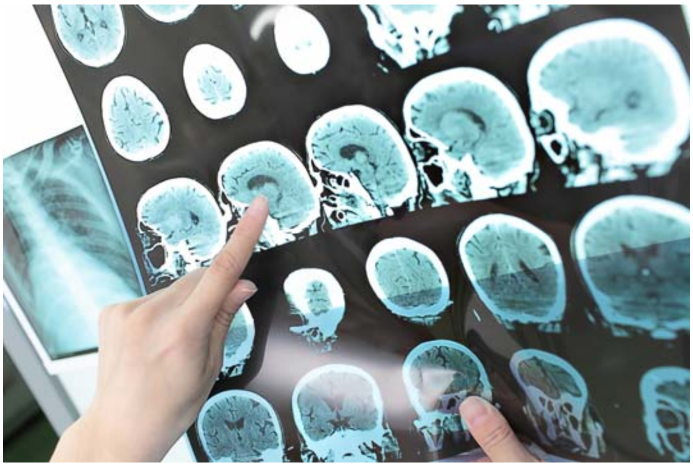
Given a diagnosis of relapsing-remitting MS in May 2007, I had no idea what this meant. But as my husband and I discovered more about the condition, the more scared we became.

Being told you have a long-term degenerative and crippling disease and an uncertain outcome is to drop a bomb on all your relationships. Including the one with yourself. All your certainties dissolve, and the future no longer looks like a place you recognize or want to visit. In the face of my husband's almost pathological fear of illness and hatred of hospitals I began to lose confidence in our marriage. Would he have signed on the dotted line if I'd had MS at the time?



In my friendships, how could I be a good friend when the randomness of the fatigue and bouts of dizziness mean you pull out of things at the last minute? As a mother, what value would I have if I couldn't actually do anything, if I couldn't even hug my daughter (then just 8 years old), let alone make her dinner, or help her into her pyjamas?

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MS is still little understood except that long-term prognosis is better if effective treatment is delivered early. But doctors often initially mistake it for something else and consultants delivering the diagnosis are not necessarily aware of the latest trials or treatments available.

So I was lucky that my neurologist is an expert in the field. He told me of an upcoming clinical trial for an oral treatment, which, in a then ground-breaking development would mean taking a pill rather than me having to inject myself.

Friends said I was mad to go onto a drug trial. But this seemed a lot less insane than trying the so-called cures that abound on the internet. And I was immediately plugged in to a brilliant medical team, fully monitored with regular check ups involving the latest hi-tech scanners. I had the number for the hotline to a particular MS nurse.

At the cold cutting edge of medical science I found a warm, comforting support network. My dialogue with my doctors was (and is) empowering. The amazing medical attention also helped alleviate the anxiety at home. The big guns of medical science were on our side. And that gave us hope.

But I knew that treatments for MS do not necessarily work in any given case. It's trial and error finding one that works for you. As part of my clinical trial I took a beta-interferon for the first year. Painful weekly injections into my thigh delivered horrible flu-like side-effects that kept me out of action for 3 days a week. But my quality of life – and that of those around me! – improved dramatically when at the beginning of year 2 I was given the active trial drug, a daily pill called fingolimod.

But what if I was just feeling better because I was off the beta-interferon? When I was diagnosed my neurologist had told me I could try and manage the condition with diet and exercise. So I also took up Iyengar yoga and tried to follow an alkaline diet.

When my yoga teacher, the brilliant Philippa Frisby said "the asanas (yoga positions) open and strengthen the inter-connection between your mind and body and the universe" My immediate thought was "Shit. I'm stuck in a room with a mad hippie!" Some years in, I know that she is actually straightforward, practical and completely right. The yoga works for me.

It involves meditation. (By which I mean just being still and concentrating on the breath). And an increasing amount of scientific evidence shows the positive impact of meditation on the brain and body at a cellular level. I also find that diet is important. I eat a load of green vegetables and go easy on processed foods, dairy, red meat and gluten heavy grains. This wards against the roller coaster highs and lows of biological responses to sugar spikes and I really do feel the benefit in terms of my energy levels and a positive frame of mind.

When I was diagnosed I felt powerless and my husband more so. We kept the details from our daughter, telling her that I might just be more tired for a while, but she picked up on the change in atmosphere. We were all suddenly at the mercy of a capricious condition where my body could simply refuse to be controlled. "Put one foot in front of the other? You're having a laugh!"

I was terrified that I could have no impact on its outcome. Ten years on I know that's not true. In any given moment we can control how we act or react. I've learnt not to panic when new symptoms occur (stabbing pains, numbness, pins and needles…) because with time you learn that they don't necessarily mean anything much, except maybe you should rest or readjust your diet, or get out more in the fresh air, (or do some yoga!) You learn to re-adjust your habits to look after your long-term health. You learn when to say yes to things and when to say no, and you learn to be grateful for everything that you *can* do on a daily basis.

Thankfully I am still mobile. The hope I was given by my neurologist at the outset and through participating in the clinical trial and the positive outlook that hope inspires are crucial to long-term health. This isn't to advocate an idiotic Pollyanna approach, but to think practically about what you can do every day to maintain your optimum health and wellbeing whatever that might be. It may be as simple as having a nap when you need one. Or if you're at work, moving your desk nearer to the loo or the lift. I've learnt that our value lies not in what we *do* for others but that it's how we *are* with them that matters. And that if we feel good about ourselves then those around us benefit.

MS is different for everyone, but its diagnosis is always shocking. MS changes your life, but it doesn't mean having to give up on it. My friend Al has Primary Progressive MS and is completely paralysed from the neck down. Reliant on 24-hour care, he recently realized his long-held dream of visiting friends and a first love (whom he hadn't seen for 40 years), on the magical Scottish Western Isle of Iona. In defiance of the gloomy predictions of his medical team he made the 500 mile journey from his West London home.

For me, work meant the chance of going to Ethiopia to stay with a remote tribe when I'd just started on the clinical trial. I rang my soon to be long-suffering MS nurse. What if I have a relapse at the bottom of the Rift Valley? " You can have a relapse anywhere, anytime, Elizabeth. You've got one life. Live it."

Feeling well

Not long ago I met an amazing woman: happy, outgoing and positive about life – despite having life-limiting arthritis, chronic pain and severe restrictions on her movement. For her, life was a blessing, and an opportunity to get out, to make new friends and to help other people.

She had found a way of dealing with those times when she felt tired, grumpy, unfairly treated, unhappy, alone and depressed. It really made me think. Her physical condition was poor, but mentally she was in top order. She felt good.

These days there's a trendy word for feeling good and functioning well. It's called 'wellbeing'. According to Oxfordshire Mind it includes feeling positive, having a sense of purpose and belonging, and being able to cope with problems and change. Lovely, but what about if you don't feel like that?!

Oxfordshire | mind
for better mental health

We all know that there are ways of keeping well physically, and importantly there are also practical steps to improve your wellbeing. Sometimes you won't feel like it, especially if you have a chronic physical illness but even if you haven't. You feel frightened, demotivated and tired. The message of this article is give it a go anyway. This stuff does work.

Mind list five things you can build into your life to make a positive difference to how you feel.

- **Connect:** with family, friends, neighbours, join a group or club, get out and help others (e.g. via the local befriending service or via Mind).

- **Be active:** go for a walk, garden, dance, just step outside. Exercising at a level that suits you makes you feel good.

- **Take notice:** be curious, savour the moment, reflect on all the good things.

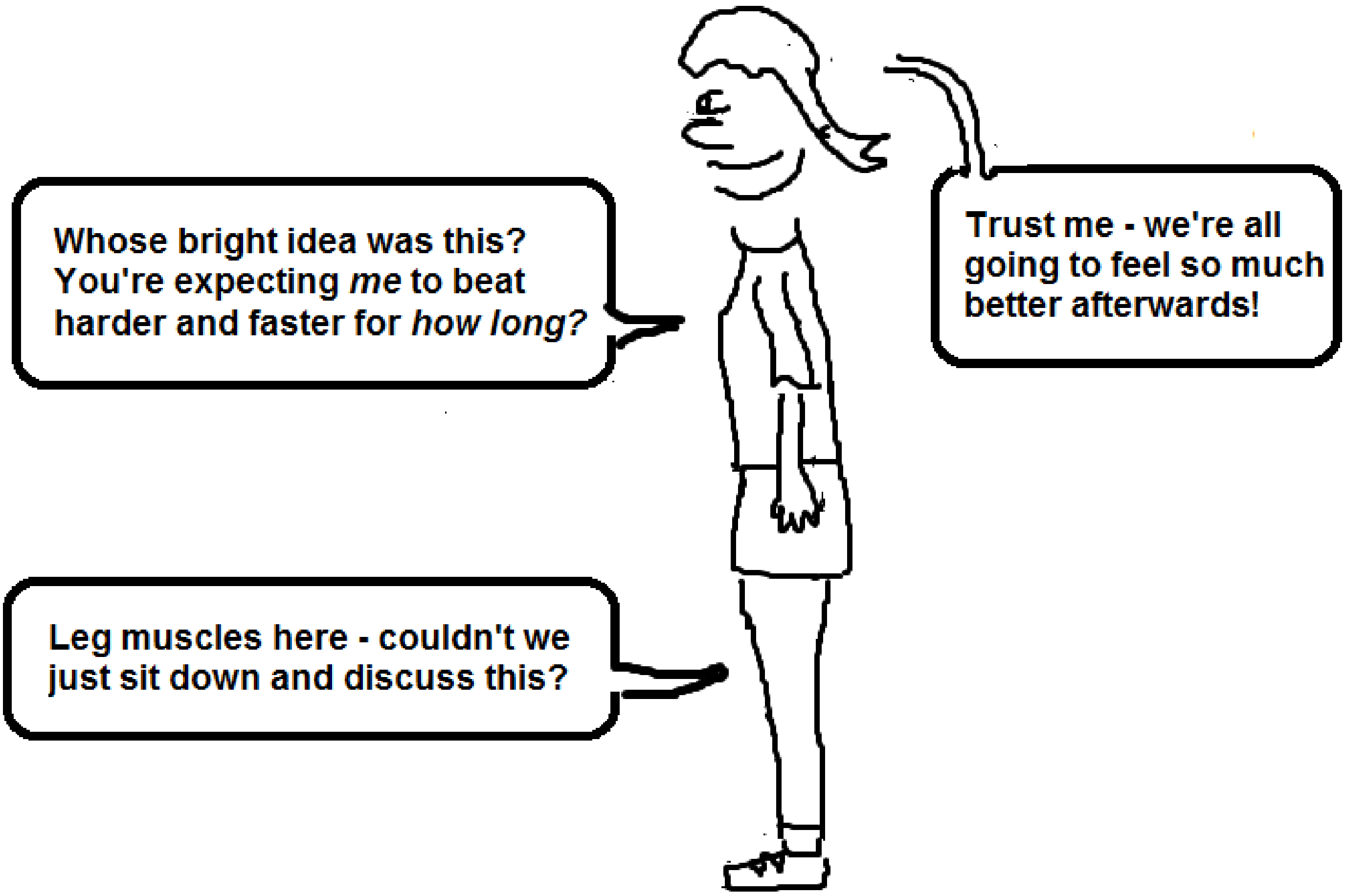
- **Keep learning:** try something new, rediscover an old interest, set yourself a new challenge, sign up for a course, cook a new recipe.

- **Give:** do something nice for someone, say thank you, smile, volunteer your time, join a charity.

If you'd like some more information on all this, have a look at www.oxfordshiremind.org.uk.

They love helping people, and are always looking for volunteers. They can also sign you up for a mindfulness course which will make you feel better regardless of your starting physical or mental state.

Wellbeing Marathon START



From the Practice

Dr de Burca will be leaving us at the end of July. He has been Dr Morrish's maternity cover and he has done a great job. We will miss him but we are pleased that Dr Morrish will be back with us at the beginning of September.

Dr Lawrence is on Maternity leave until the end of January 2018. There will be two locum GPs covering her absence: Dr Kirsty Shepherd, who some of you will know, and Dr Kate Trivedi. Both GPs will be here from the beginning of June until the end of January next year. We will also have some extra help from Dr Linda Jones in August.

Sarah Bright has been with us for 2 months now. She is an Advanced Nurse Practitioner (ANP) and has joined the two Emergency Care practitioners (ECPs) in managing the urgent/same day requests.

Dementia Oxfordshire
Connect • Inform • Support

Groups in Witney for People Living with Memory Loss

Creative Moves

A music and movement group for people with memory loss and/or Parkinson's

No group in July and August

Tuesday 12th September
Tuesday 10th October
Tuesday 14th November
Tuesday 12th December

Fernleigh, Buttercross Lane,
Witney, OX28 4DZ

10.30 – 12.00

£3, carer goes free

Call Julia Pool for more details:
07827 235426

Music for Wellbeing

A music and singing group for people with memory loss and their carers/families

Tuesday 4th July
Tuesday 1st August
Tuesday 5th September
Tuesday 3rd October
Tuesday 7th November
Tuesday 5th December

The Upper Hall, Methodist Church, High Street,
Witney, OX28 6HG

10.30 – 12.00

£3, carer goes free

Call Julia Pool for more details:
07827 235426

Golden Memories

A monthly coffee morning for people with memory loss and their carers/families.

Come and have a chat, reminisce, and have fun!

Thursday 20th July
Thursday 17th August
Thursday 21st September
Thursday 19th October
Thursday 16th November

The Wesley Room, Methodist Church,
High Street, Witney, OX28 6HG

10.30 – 12.00

Call Julia Pool for more details:
07827 235426

(Donations towards refreshments would be gratefully received)

Evidence Matters

by Sarah Chapman

I work for Cochrane UK, the UK hub of an international network of people working together to help people make informed decisions about health care. It does this through doing systematic reviews, which bring together the results of clinical trials to answer questions about what helps or harms in health care.

Creams and gels for pain: what do we know about how well these work?

There's quite a choice of things to rub onto painful areas, including creams, gels and plasters, some contain drugs, others things like chilli or plant extracts. Some are designed to cool the painful area and others to produce a sensation of heat. How to choose?

The evidence

A Cochrane overview has drawn together the best available evidence on this, with information from 206 trials with around 30,700 people. The main focus was whether people with moderate or severe pain had their pain reduced to no worse than mild pain with treatment.

The creams, gels and plasters were compared with placebo (dummy) preparations that were identical, and applied in the same way, except they had no active ingredient. This way, we know that any difference between the two wasn't due to the action of rubbing, for example.

They found the following,

- For acute pain conditions (like sprains and strains) two non-steroidal anti-inflammatory gels, a diclofenac gel and a ketoprofen gel, gave good pain relief in 70-80% of people after about a week. This was 40-60% more than with placebo.
- The gel products worked better than the same drugs in creams and plasters.
- For chronic pain conditions, like osteoarthritis, these same gels produced good pain relief, after about a fortnight, in just 15-20% more people than a placebo gel.
- Quite a lot of people with chronic pain got good relief with the placebo gel! Of those who had placebo gel or ketoprofen/diclofenac gel, 40-60% had good pain relief.
- For many topical products, including herbal remedies, menthols and some drug preparations, there is no evidence of how well they work, or so little that we can't trust it.

How about side-effects?

These products work close to where you apply them rather than through your whole body so, while some people may have a bit of itching or redness at the site, other side-effects are rare.

Keeping Well? is committed to evidence-based healthcare, but never makes any recommendations about particular drugs for particular patients. These are solely a matter for the patient and his or her doctor.

You can see the review in full at www.thecochranelibrary.com.

ARTICLE details

Derry S, Wiffen PJ, Kalso EA, Bell RF, Aldington D, Phillips T, Gaskell H, Moore RA. Topical analgesics for acute and chronic pain in adults – an overview of Cochrane Reviews. *Cochrane Database of Systematic Reviews* 2017, Issue 5. Art. No.: CD008609. DOI: 10.1002/14651858.CD008609.pub2. Available from: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008609.pub2/full

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