

The Belle

Issue Number 81

Summer 2018

We are sorry to announce that Ben Bloom, our Centre Manager, is leaving on July 25th to take up a post in London.

Ben has achieved a tremendous amount since he arrived at the Centre in January. We had a number of outstanding issues which he set about resolving with determination, navigating his way through bank call systems and other administrative issues with patience and tenacity. Ben introduced a simplified card payment system, much to the delight of all our receptionists, researched countless databases to find a suitable replacement for our aged Access version, took on the new data protection regulation and made a lot of cakes! He was also instrumental in the recruitment of Emily, our wonderful new Operations and Fundraising Coordinator.



Ben pictured with local author Bryony Hill at St Lawrence Fair in Hurstpierpoint

We are very grateful to him and wish him all the best for the future.

Southwick Recreation Ground, Croft Avenue, Southwick,
West Sussex, BN42 4AB

www.mssussex.com

01273 594484

Treatments and Classes Available at the Centre

Hyperbaric Oxygen Therapy (HBOT)

Everyday. Contact the Centre for times and availability

If you haven't tried HBOT yet, we recommend it for long term management of MS. It can also lessen the severity of your symptoms.

Classes

All our classes are mixed ability drop in, so come along and try them out to find which one/s suit you. All free, although a donation is always appreciated!

🌀 Keep fit: Tuesday and Thursday

🌀 Pilates: Monday and Thursday

🌀 Yoga: Wednesday

🌀 Physiogym: Friday

🌀 Tai chi: Wednesday

🌀 Voicework: Friday

🌀 Seated exercise: Thursday

All very different, but all with the same aim: To help you work with others to maintain and improve your physical abilities and promote wellbeing and a positive attitude.

Individual Therapies

We host a wide range of individual treatments. All our therapists are self employed and charge between £15 and £20 per session, paid directly to the therapist except for physiotherapy which is paid to reception. Speak to us if you would like to know more about what's on offer. Book appointments at reception.



I'M LATE, I'M LATE!

To get the maximum benefit from your session in the hyperbaric chamber you should be calm and relaxed, so please try and arrive at least 15 minutes prior to your session. This will also help us run the sessions on time.

Dear Friends,

Well now - I didn't think I would be writing a goodbye article in the Belle so soon, but as many of you all know, life doesn't always stick to our best-laid plans! You no doubt already know that I am leaving the Sussex MS Centre to relocate to London, and whilst I am really excited about my move, I am very sad to be saying goodbye to you all. As I say farewell, I should like to say a few final words of thanks.

Firstly, my very special thanks go to Jane and Alan Taylor who have been such steady guides throughout my time here. Their dedication is undeniable, and the Centre has much to thank them for. A big thank you also goes to Emily who joined the team here at much the same time as me. We are incredibly lucky to have found someone with such abundant energy and enthusiasm, and I am so thankful for all that she does for the Centre. I'm also so grateful to the trustees who have been incredibly kind and supportive throughout my time here. They truly have the best interests of the Centre and its members at heart, and I am certain that you will all continue to support them whilst they recruit a new Manager. And finally, the many people who volunteer their time and skills at the Centre are so irreplaceable! Without our volunteers we would not even be able to open the doors. I am so grateful for the invaluable help that they have given me during my time here. Thank you SO much!

The membership at the Sussex MS Centre is so varied, that in any one day you will meet 10 or more totally different types of people. I am in awe of how you all come together in difference to support one another, to share in community, and benefit from the experiences that you all share. This Centre is such a nurturing and positive place to be, and that's because you all make it so. The staff and trustees are just the pegs keeping everything down, but you wonderful volunteers and members are the vast canvas of the tent that gives everyone a home. I'm so grateful that I have also been able to call this place home for a while. I hope that this dynamic and vibrant community continues to flourish and grow for many years to come.

With much love,

Ben



Sleep... or lack of it.

Chatting to people at the Centre, it is very apparent how common poor sleep is amongst us. The MS Trust estimates that about 50% of people with MS experience some form of sleep disturbance. Despite this being well known, sleep disorders are under-diagnosed and under-treated in people with MS.

Poor sleep quality and quantity can impact on daily life, causing daytime sleepiness, decreased concentration and memory, worsening depression, and the inability to work effectively. A lack of sleep can also lead to low energy levels or make pain, fatigue, and other symptoms of MS much worse. The types of sleep problems that you may experience include difficulty falling asleep, difficulty maintaining sleep (such as waking up during the night or not being able to fall back asleep immediately) and early wakening. Speak to your GP or MS team if sleep problems are affecting you. There may be treatments that can help. By addressing the causes of poor sleep quality, you may find you can improve your overall energy levels and quality of life.

Possible Causes of sleep disturbance in MS

There can be many reasons why getting good quality sleep is difficult:

These include:

- spasms,
- pain (neuropathic or musculoskeletal),
- restless legs syndrome
- anxiety and/or depression
- side effects of certain medications
- nocturia (the urge to urinate frequently at night)
- sleep apnoea (abnormal pauses in breathing)
- high levels of daytime fatigue.
- managing responsibilities that mean less time is available for sleep

- concerns and worries that make it difficult to 'switch off' and drift into sleep or produce restless sleep
- being sedentary or less active can alter sleep patterns
- a lack of exposure to daylight during the day can affect sleep patterns
- a lesion in the region of the brain responsible for sleep can affect sleep patterns

Treatment and management

Identifying and then treating sleep disorders can improve other MS symptoms, particularly cognitive function, fatigue, depression and pain, helping to improve quality of life.

Many symptoms that can cause sleep disturbance are treatable. If you are currently not receiving treatment for them, or if the medication you are taking is affecting your sleep, do speak to your MS nurse. Changing your medications or altering the time you take the treatment could help. For example, treatment options for pain can include medications such as gabapentin, which has been shown to improve nocturnal pain and also promote restorative sleep.



The beta interferon disease modifying drugs (DMDs), including Rebif, Avonex, Plegridy, Betaferon and Extavia, are known to affect sleep efficiency on the day treatment is taken. Usually, the advice with these drugs is to take them in the evening, so that you can sleep through the side-effects. However, some people prefer to take them in the morning, if the side-effects are manageable, as then their sleep is less affected.

On the positive side, some MS treatments have positive effects on sleep. Two studies have shown that natalizumab (Tysabri) treatment improved fatigue and sleep patterns. There is no evidence for other DMDs and their impact on sleep. Cannabis and medicinal extracts of cannabis are associated with improved sleep patterns, reduced sleep disruption and reduced depression. These effects may be directly due to the cannabinoids taken, or indirectly due to reduced spasticity and pain as a result of the treatment.

Even without speaking to your MS nurse, you could try a few things that may help. Sleep quality can be improved by establishing regular habits or good 'sleep hygiene':

- try to stay as physically active as possible during the day, but allow plenty of time to wind down before bedtime
 - avoid getting overtired by doing too much, as being too tired can make it difficult to get to sleep
 - ensure some daily exposure to sunlight and avoid bright lights in the evening
 - avoid stimulants (eg caffeine, chocolate, alcohol) in the late afternoon and evening
 - keep the same nightly ritual every day throughout the week
 - establish a bedtime routine that can include, for example, relaxation, a warm 'milky' drink, taking a warm bath
 - don't use screens for half an hour or so before you wish to sleep
 - instead of lying in bed awake, after 15 minutes of not sleeping get out of bed and do something calming or boring, and return after a short period of time
 - avoid getting too hot; although some people find having cold feet can also disturb sleep
 - speak to one of our therapists.
- Many of the treatments we offer here can help to promote restful sleep.



Thanks to the MS Trust.

Volunteer!

We can't survive without you. If you can help for a couple of hours per week, or a couple of hours per year, you will be making an essential contribution. We spend less than £150,000 per year running our Centre... what an extraordinary amount we do for so little. And that's all because of our valuable volunteers.



**The Queen's Award
for Voluntary Service**

The MBE for volunteer groups

What a ride!

This June we had 23 cyclists join us for our annual 20 mile sponsored bike ride following the Downs Link from Shoreham to Slinfold.



The sun shone all day for us, welcoming a few new faces to our annual ride, along with a great group of return cyclists from previous years. This year our team managed to raise well over £3500 in sponsorship for the Sussex MS Centre which is an amazing effort all round. Like all of our sponsored events, it wouldn't be possible without our wonderful team of volunteers, from our marshals handing out snacks and water along the way, to Pete following the team armed with his puncture repair kit, our friends at Rossetts in Worthing who kindly provided a van to drive all of the bikes back to Shoreham, the marshalls who guided them on the route and of course the volunteers at Slinfold preparing an array of delicious sandwiches and treats to welcome the cyclists at the finish line. Our next sponsored event is coming up in September with a fundraising walk from Shoreham to Upper Beeding and back.



River Adur Sponsored Walk

Saturday 1st September

Round route

Shoreham Airport - Upper Beeding



Sign up at reception or email events@mssussex.com

Please recruit friends and family for this delightful day out!

May Open Meeting.

As promised at the Open Meeting in November, your trustees **held a follow up in May where they** focused on improving communication between members, staff and trustees.



The meeting was structured as a workshop, facilitated by centre member Lin McCallum Stewart. Participants identified a number of areas that we felt were done well, and then those that needed improvement. At the end of the meeting, these were prioritised.

Several actions have already been undertaken and others, such as website improvements, are in hand. Our thanks go to Lin for her hard work. Full minutes of the meeting are available at the Centre or can be sent to you if you contact reception or info@mssussex.com.

We would like to reiterate that if you have any concerns, you can speak to a trustee or jot them down in the Comments Book. All comments are discussed by the staff and your trustees at meetings or before if we consider that action is required. If you wish to raise an issue privately, please post it into the box under the Committee noticeboard or write directly to our Chairman, Chris Ash Edwards, c/o Sussex MS Centre.

Annual General Meeting



This year's AGM (my first as chairman) was held on 18 June and had the best attendance during recent years. I would like to thank all those who made the effort to attend.

Members approved all those standing for election or re-election to the board. As Derek Aitken didn't stand for re-election, I would like to thank him on

behalf of the committee for his contribution over many years both as a trustee, treasurer and chairman. I am also very pleased to welcome Jill Brookes back as a trustee.

Members also agreed, subject to the consent of the Charity Commission, for the Centre to become a Charitable Incorporated Organisation and adopt a new constitution. This will enable us to have a modern structure and a clearer set of rules for the future.

There was also a vigorous debate on membership criteria and the trustees have agreed to keep this under review.

The Trustees meet bi-monthly on the 3rd Monday of the month. The next meetings are July 16, September 17, November 19. Your trustees are Martin Bennett, Jill Brookes, Alison Clough, Peter Cook, Christopher Fox Walker, Virginia Keefe, Nikki Manchee, and Alan Taylor. Our chairman is Chris Ash Edwards. If you wish them to address any issue at one of the Board Meetings, please put it in writing in the Comments Book or if you wish it to be private place in an envelope addressed to Chris Ash Edwards, c/o the MS Centre, put it in the suggestion box or email info@mssussex.com.

Thank you.

Please note:

If you do not wish to receive a paper copy of the newsletter, please ring the Centre or email jane.taylor@mssussex.com. Our Board of Trustees recently voted to continue sending out the paper copies, as we like to keep you and your families informed about what's going on at the Centre and with MS support... and how you and your friends and family can help us carry on!

Information is available via Facebook and we are in the process of improving our website, which we expect to have a members area.



Follow us on Facebook. Search for Sussex MS Centre. It's an easy way to keep up to date with what's going on at the Centre.

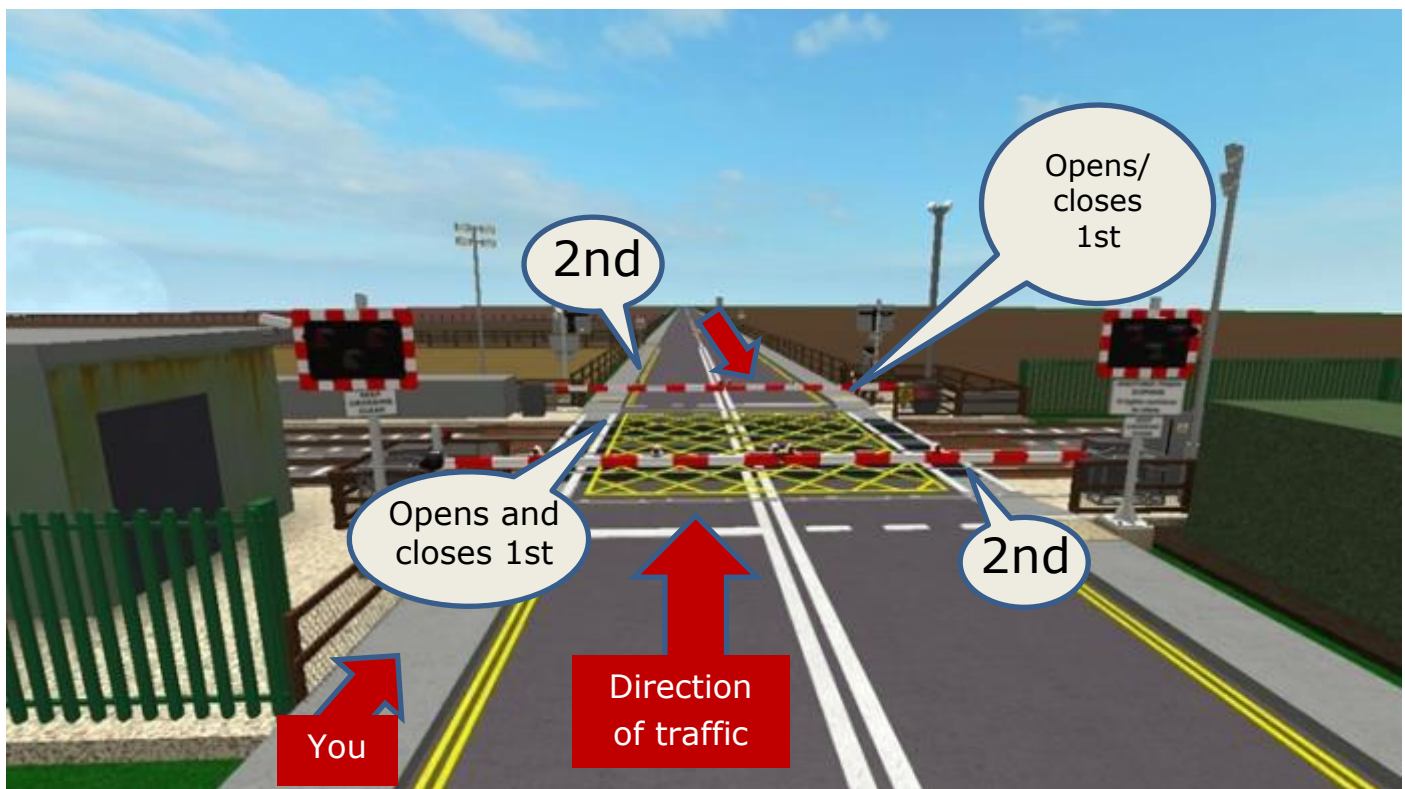


Safety at Level Crossings

We have quite a few level crossings along the south coast, Shoreham and Portslade being two examples. Crossing on foot, with a walking aid or in a wheelchair can be a little nerve wracking, particularly if there is a lot of pedestrian traffic. To lessen the risk, the following advice is given.

To maximise the time allowed to cross, always choose the side that crosses with the flow of the road traffic. With the double barriers, the exit barrier comes down after the entry barrier, giving more time to clear the crossing.

And of course, never set off once the lights and alarm has started, even though it can be frustrating having to wait.



Network Rail do everything they can to keep us safe, but we hope highlighting this will help to prevent incidents.

On sale here!



Following recommendations from some members, we now sell these supplements. We source top quality products and strive to offer them at a lower rate than commercial suppliers.

We're happy to investigate any of your suggestions to see if we can source good quality supplements at a discount.

Vegan Treats!

Date and Nut Balls

Makes 20

200g dates (pitted)

60g walnuts

60 g almonds or cashews

1-2mls vanilla essence

Blitz the nuts until they are like crumbs.

Add the rest of the ingredients and process until well combined.

Roll the mixture into 1" balls and then roll them into a topping of your choice, such as toasted sesame seeds, toasted coconut, chopped pistachio or cocoa powder.

Chill in the fridge to set.

For variety you can use other nuts of your choice, replace dates with other dried fruits such as apricots and use cinnamon, ginger or almond essence to flavour.





A big thanks to our friends at Lloyds bank for kindly volunteering their time to work tirelessly under the beating sun in early June to spruce up the front of the Centre and our back garden ready for summer!



BBQ

with **cool** jazz

Sunday 19th August

Doors open 1 pm

Members £4, member + 1 £6, guests £6



**Celebrate the
60's**

**Food, quiz and
fun...**

**Sunday 23rd
September**

Doors open 12.30

**Further details closer
to the time!**

MS Specialist Nurses

Brighton	Stephanie Verry or Nadia Abdo	01273 265887	stephanie.very@nhs.net
			n.abdo@nhs.net
Worthing, Littlehampton to Southwick	Julie Green or Nicky Davis	01903 858178	julie.green11@nhs.net nicola.davis4@nhs.net
Eastbourne, Seaford & Hailsham	Vicky Lester	01323 514809	victoria.lester@nhs.net
Chichester & Bognor	Katrina Orchard	07768 145978	katrina.orchard@nhs.net tr.msteamworthing@nhs.net
Horsham, Crawley & Chanctonbury	Nadine Morley	01403 227000 Ext. 7669	nadine.morley@nhs.net
Uckfield	Gill Ferdinands	01825 769999	gill.ferdinands@nhs.net
Bexhill, Hastings & Rother	Trish Dean	01424 755255	trish.dean@nhs.net
Mid Sussex & Crawley	Kelly Hill	01444 419532	kelly.hill4@nhs.net
MS team email	sc-tr.msteamworthing@nhs.net		



We had a great summer lunch with Worthing Steel Band and Andy and Pete on the bbq's, Stephen's walking the Southdowns Way, Matt is going to throw himself out of a plane, Di, Kath and Ali ran a great stall at the Lions Donkey Derby, Joe and Pete represented us at Mile Oak Farm Open Day. Thanks to them and everyone else who has contributed to help us keep our prices down for you all. If you can assist in any events, please speak to Emily.



SPRING 2019



BRITISH AIRWAYS

i360

i360 Fundraising Abseil

Drop 450ft from the British Airways i360
and raise funds for the Sussex MS Centre

Saturday 27th April 2019

Email events@mssussex.com for more information



SUSSEX
MS CENTRE
small charity, big impact