



Sussex MS Treatment Centre

Southwick Recreation Ground
Croft Avenue
Southwick
West Sussex
BN42 4AB
01273 594484

www.mssussex.com

Charity Number: 801075



-Small Charity-

-Big Impact-



Welcome to the spring edition of your centre's newsletter.

Since the last issue of The Belle, we have had a great Christmas lunch at the centre and lots of us enjoyed our Burns Supper, complete with Haggis, Tatties and Neaps, a glass of single malt and a Scottish sing-a-long with Silkie Moon, and, of course, some Burns poetry from Bob. We're looking forward to the spring programme of events, including a St. Patrick's Day party and our popular quiz with fish & chip supper. See inside for more details and come along!

Don't forget that fundraising is essential to help us keep our services more affordable for all of you. There are plenty of fundraising activities listed for you to get involved in, our members have always done a fantastic job raising the money to run the Centre so please join us and help to lighten the load.

The Sussex MS Centre came into being in 1983 as part of ARMS (Action Research for MS). Following the demise of ARMS, we joined MS National Therapy Centres who have acted as the umbrella organisation for MS Centres throughout the country. For some time

your committee have been concerned about the way MS National has been run and with regret have decided that we should leave. This will, in no way, affect the service the Sussex Centre provides to its members.

We are also considering the possibility of building a brand new centre. This will be a long term project and is still in the very early stages of development, but the committee would appreciate hearing from you with your comments and ideas.

On a personal note, I have decided to retire later this year, having been here at the Centre for 18 years. So that's another excuse for a party!

Alan



Most Spectacular

Fashion Show

Worthing Assembly Rooms

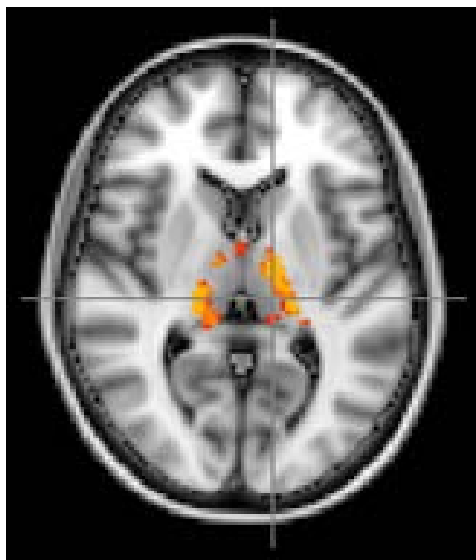
Thursday 15th May

7.30 – 10pm

Tickets £10 - £15

Book online at <http://www.worthingtheatres.co.uk> (booking fee) or in person from the Pier or Connaught Theatre, Worthing box offices, or contact Jeannette Jones via the Centre or on Facebook.

New 'SMART' Trial for SPMS



Multiple Sclerosis - Secondary Progressive Multi-Arm Randomisation Trial

There are currently no proven treatments for the stage of MS known as Secondary Progressive (SPMS). This is the stage of the disease which results not in individual attacks but by a slow, cumulative increase in disability.

A new trial is starting to evaluate three drugs (ibudilast, riluzole and amiloride) all of which have shown some promise in MS and in particular in SPMS when compared to placebo. The assessments will take place over two years and include clinical and MRI evaluation.

The main criteria for taking part are:

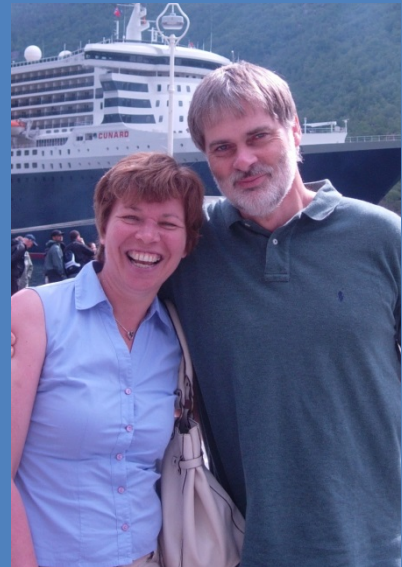
- Secondary Progressive MS
- Not on any other disease modifying drug
- Still able to walk at least 20 metres (even with the support of two crutches or up to 500 metres without aids)
- Aged 25 -65

If you are interested in participating, go to www.ms-smart.org or speak to your MS nurse or neurologist.

The trial is supported by:



Your Trustees



From left to right, top to bottom, in no particular order:
Derek Aitken, Gill Barnes, Barbara and Mark Randall, Martin Bennett, Nicci Manchee,
Ruth Schofield, Virginia Keefe, Jill Brookes, Debbie Kennard

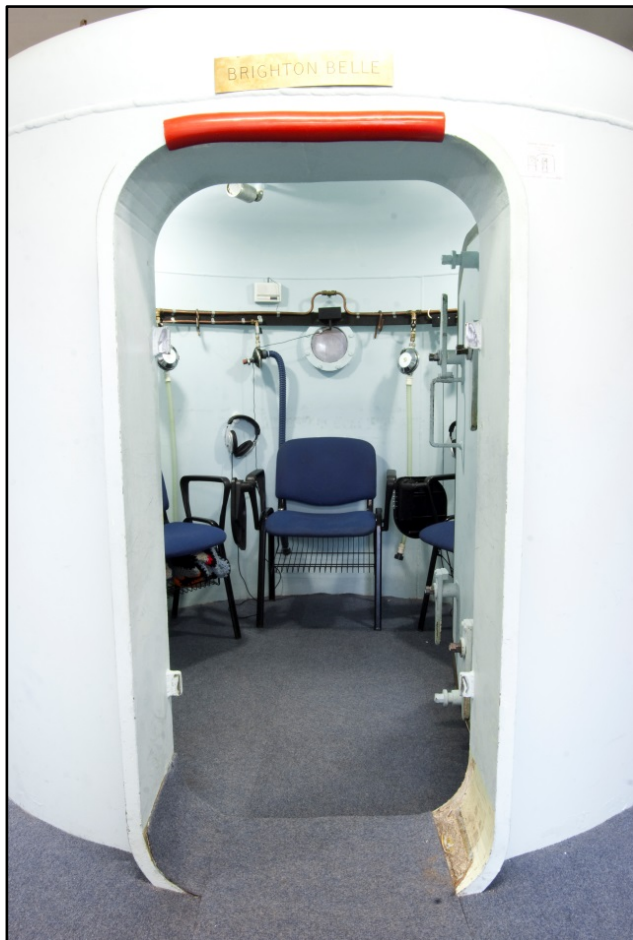
Your Trustees are here to represent you.

The Board of Trustees meets on the 3rd Monday every other month. If you have any concerns or suggestions on how to improve the service we offer, than please don't hesitate to talk to one of your representatives.

Hyperbaric Oxygen Treatment

Many of you will have been aware of how busy the oxygen chamber has become and some of you have experienced problems in booking dives. In order to address this we have reluctantly decided not to accept non-MS users for the time-being. Our charitable purpose is to work for the public benefit of people with Multiple Sclerosis and chronic neurological conditions, but historically we have always tried to support anyone with a health condition that would benefit from the specialist treatment of Hyperbaric Oxygen Therapy. This cannot however, be to the detriment of our MSers, either because they are unable to access the treatment, or that they are subsidising those with other health conditions.

From the 1st February HBO will be £18 for new non-MS users. Those with MS and other neurological conditions and existing members will continue to pay at the current rates. We will monitor and review these changes on a regular basis. We are also following up those who miss



their scheduled dive reminding them that this affects others and asking them to remember to phone us and let us know with as much notice as possible if they are not able to get in.

We've added an additional 1.75m 'dive' at 1.30pm on Mondays and will continue monitoring the situation.

Please write in the comment book at reception if you have any thoughts on this matter, and it will be reviewed at the next meeting of the Board of Trustees.

Sebastian Best writes:

My name is Sebastian Best, I am 41 years old.

The first indication that I was ill was when I was playing rugby at age 8. Every time I was tackled it aggravated my nerves and I developed a stutter. Later, at the age of 32, when I was working as an electrician at Sussex University, I fell down the stairs at home. I was still able to walk after this but I kept falling over.



It took 2 years to convince the doctor that I was ill and to get an MRI scan followed by a lumbar puncture. Results showed that I had highly active relapsing / remitting MS. Numbness and tingling started in my hands and feet which spread all over my body and up my arms and legs and when it joined at the back of my neck, I just thought HELP!

I heard about a neurologist in Brighton called Dr Romi Saha who does Medical Trials for MS and I went to see him. He got me onto a trial in Charing Cross Hospital in London, which is renowned for its medical trials. I was put on a two year treatment of Mitoxantrone, which basically halted the progression of my MS. I also took Pregabalin which helped with nerve pain and Baclofen which is a muscle relaxant which helps with tremors. I have now been on Tysabri for 3 years.

I also have the JC (John Cunningham) virus which, when taking Tysabri, can increase the risk of contracting the brain disease PML so I have blood tests every 3 months to check my health.

Alongside the drugs which I have been prescribed I've been encouraged to use vitamin supplements and also to eat organic food to improve my health. I find the HB Oxygen tank beneficial and "dive" every week.

I take the following Vitamin Supplements :

Magnesium - for bones and teeth, it also helps tiredness and fatigue, transmission of nerve impulses

Zinc – Healthy Immune System

Ginkgo Leaf - Good for cognitive function.

Omega-3 from Krill Oil - Supports the Immune System

Vitamin D3 5000IU - The sunshine vitamin, helps with the Immune System and bone health.

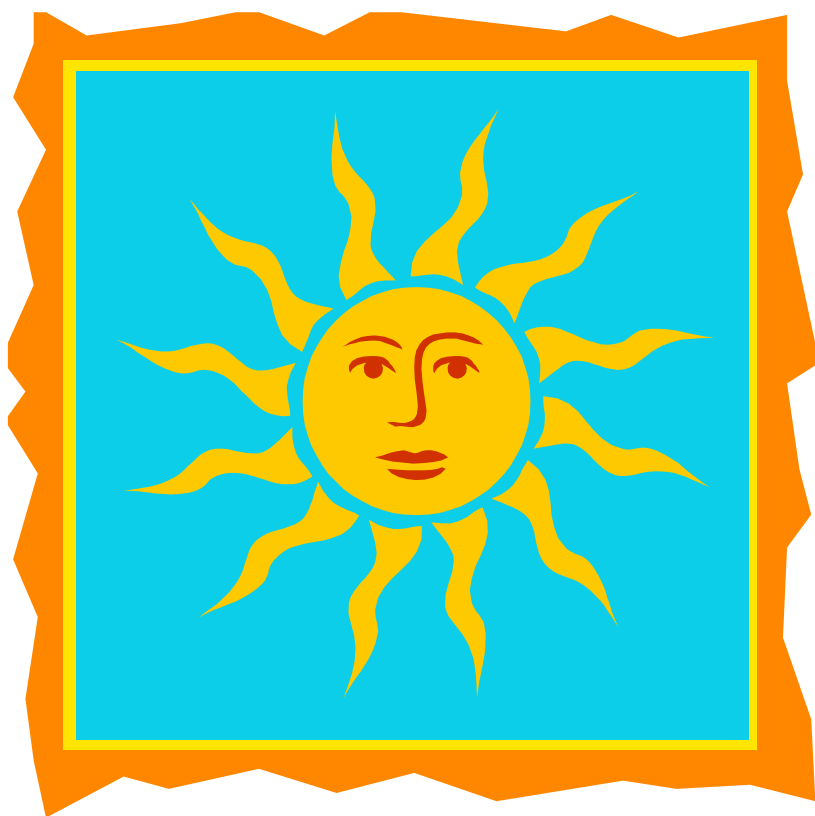
Complete Vitamin B Complex - Helps just about everything!

Multi Vitamins

I eat prepared organic meals from Wiltshire Farm - brochures are available at the centre.

Dr Saha is a Consultant Neurologist at the Royal Sussex County Hospital in Brighton.

ON SALE AT THE CENTRE



VITAMIN D

THE SUNSHINE VITAMIN

ONE A DAY

5000ul

£11

365 tablets

A whole year's supply of this vital supplement for less than a pound a month

As reported in your last newsletter, increasing numbers of health professionals with knowledge of MS are recommending this supplement.

facebook

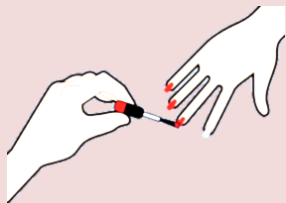
Don't forget you can follow us on Facebook and keep right up to date with what's on at the Centre

18th May : MS Trust Goodwood Challenge: A good day out!

THE MOST SPECTACULAR PAMPER EVENT

Saturday 29th March

10.00am until 16.00pm



Now in its 3rd year, the Most Spectacular Pamper Event is a chance to have a very girly day of trying mini treatments, buying and trying a wonderful selection of beauty and skin care products and supporting this us at the same time!

£2.50 entry includes a complimentary drink on arrival.

Goody bags for the first 100 people through the door

Most Spectacular Pamper Day Raffle!



First Prize: 2 return flights to New York *

Second Prize: Body shop hamper worth over £50.00

Third Prize: Chocoholics Chocolate hamper worth over £50.00

And many more smaller prizes

Tickets available at the Centre £1 each, £5 book of 5

* Two economy class return tickets to New York on Virgin Atlantic, valid until March 29th 2015.

You will not be able to book your flights during the following travel periods: 10 days either side of Easter 2014, 20th July - 12th September 2014 and the 15th December - 15th January 2015. The winners of the flight will be responsible for their own accommodation costs, visa, passport and insurance requirements.

Star Volunteer

We were thrilled when Jeannette Jones won a Shoreham Herald and Gazette Community Star Award. She certainly deserved it! We all owe her a debt of gratitude for her fantastic and continuous commitment to the Centre.



On 3rd December Jeanette organised a dinner for our members and their friends and families at the Sussex Produce Company in Steyning. This was the last of a number of fundraising events organised by Jeanette during 2012. She raised several thousand pounds for the Centre with her Most Spectacular Pamper Day and Christmas Fayre, both of which have become annual events.

The evening in Steyning was well attended and a delicious meal served by the very attentive staff. It was enhanced by Leon, the magician, performing close up magic. Hopefully there will be another dinner in the coming year and do look out for further pamper day events and a fashion show, as advertised in this Belle, at the Centre, on our Facebook page and website.

Get your thinking caps on...

The **quiz** is back!

Friday April 11th

Doors open 7 pm

£7.50 inc Fish & Chip Supper

Licensed bar

Make your own team or join one on the night



Dates for your diary:

Fundraising Events 2014!

WE NEED YOU!

Every contribution, no matter how small, will help us to raise the £250,000 we'll need to run the Centre in 2014. This way of raising our much needed running costs is very effective, and what's more it's fun!

Saturday 29th March

The Most Spectacular Pamper Day



Come along, shop and be pampered

Sunday 6th April

Brighton Marathon

Join one of our cheer points to help them on their way, it's a great atmosphere.



Saturday 19th April

Owls out and about for MS

Sainsbury's Supermarket, West Hove Supermarket Collection

We'll need volunteers to represent the Centre and even hold an owl!

Thursday 15th May 7.30pm

The Most Spectacular Fashion Show

Worthing Assembly Hall



Sunday 1st June

Sponsored Seafront Bike Ride

Help us to find participants, marshall for an hour or so at one of the points, or assist in providing the end of ride picnic



Sunday 3rd August

Tandem Skydive for MS

Would you, or anyone you know, like to join our group of adrenalin seekers!



Sunday 14th September

The Adur Sponsored Walk

We'll need walkers, marshalls and sandwich makers for the picnic at the end!



and last but not least....

Most Spectacular Winter Fayre

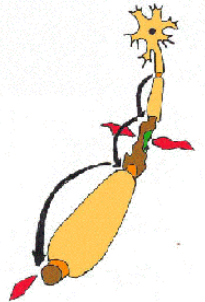
November 8th & 9th

University of Brighton: We're looking for volunteers to take part in exciting and interesting study!



The thought of struggling on an exercise bike or keep fit classes can be difficult for many people with MS who find their symptoms are worsened by heat. Cooling oneself down before, during or after activity can help to reduce the effects of heat and the problems that it can cause.

Why does this happen? The most common hypothesis: the more heat, the weaker the conduction of electrical impulse due to demyelination of the nerves temporary exacerbating symptoms. Cooling increases conductivity, prolonging the current available, meaning more current can flow through your nerves and signals are more reliable.



Now you can have the chance to try out this theory for yourself!

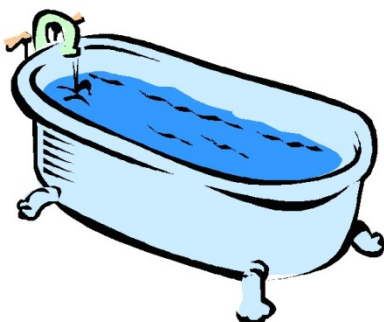


My name is Laura and I am a student from the University of Brighton. I am involved in a research study evaluating practical methods of pre-cooling for heat sensitive individuals with Multiple Sclerosis. Although research has found positive effects in thermal comfort with pre-cooling using cold water baths realistically this is a not efficient or practical



method!

Little research has been conducted using easy to use ice vests or ice shorts to see the effect on reducing



exacerbations and improving thermal comfort. If proven beneficial, individuals may be more inclined to take up physical activity in turn reducing the chance of secondary health problems associated with a sedentary lifestyle.

I am looking for volunteers that would like to be involved, all that is required is four visits to the University where you will be required to wear either ice vest or ice shorts for 20 minutes prior to completing a 20 minute cycle on a stationary bike (with the intensity tailored to the individual).

Transport and costs will be reimbursed and we are all very friendly faces! →

The future aim is to relay results back into the wider community of the MS population hoping to benefit and encourage physical activity. However, the study relies solely on volunteers, and the more that we can gather, the more reliable and valid the results found will be.

If you would like to find out more I would love to hear from you, contact either myself, or Dr Neil Maxwell who is leading the project for more information. The four sessions can take place any day of the week (although each one spaced a week apart) at any time of day, and also at weekends. The study has passed an Ethics Committee and has full support from the MS Trust and MS society.

Thank you for your time and I look forward from hearing from you!

Laura Renesto

(07841 183 295)

lr140@uni.brighton.ac.uk

n.maxwell@brighton.ac.uk



Diners at the Classes Christmas lunch in December had riotous fun whilst waiting for their Chinese takeaway. Julia loves to arrange the entertainment!



COME ALONG FOR THE CRAIC

GET YOUR TICKETS FOR THE

**SAINT
PATRICK'S
DAY PARTY**



MUSIC : IRISH STEW : LICENSED BAR : GOOD COMPANY

FRIDAY 21ST MARCH

£7.50

COME FLY WITH US!

Tandem Skydive



Provisional date: Sunday 3rd August

“It was !#*!#! AMAZING, ‘SCUSE MY LANGUAGE” Lisa McG

Contact Jo at the Centre or email events@mssussex.com for more details

Thank you, John Lewis Home Store, Chichester



Nikki, Wendy and Jo, attended John Lewis at Home Store in Chichester to receive a cheque for £961.00, which had been collected through the fantastic Community Matters Scheme, which raises funds for local community charities and

organisations.

We met the store staff to thank them for their fundraising and promotion of the Centre and to let them know how we could use the money to help fund our services.

An article about the MS Centre and the funds raised from the Community Matters scheme at Chichester will appear in the store magazine called John Lewis Editions.

New to the Centre:



HAIR CUTTING

Caroline will be visiting the Centre approximately every 4th Monday, on February 24th and March 24th

Due to our limited facilities, she will be providing a dry cut service for both sexes.

SUPPORTED SHORT BREAKS

Provided by Carers Trust and Crossroads Care Schemes in partnership with the MS Society



This new service for people with MS living in England or Wales enables you to take a break with your carer & family and be reassured that your carer is benefitting from a break from caring.

For a copy of “Our Guide to Short Breaks” contact the MS Society Information Team on 020 8438 0799 or download a copy from the website www.mssociety.org.uk/ms-support/practical-and-financial-help/holidays-short-breaks-respite-care

For grants to help with the cost contact the MS Society Grants Team on 020 8438 0700 or e-mail them on grants@mssociety.org.uk

Your local Crossroads Care Scheme assess your support needs and the destination scheme to ensure that your chosen destination can provide them.

The Sussex Care Schemes are:

Care for the Carers East Sussex 01323 738390

The Carers Centre for Brighton & Hove 01273 746222

Crossroads Care South Central (West Sussex) 01903 790270

Leaflets on this service are available at the Centre and information and advice is available from our carers network. Why not suggest they come along to our next carers day which will be advertised in the next issue?

SAINSBURY'S WEST HOVE

Our Charity Partners for a year continue to provide great support to the Centre. We held a successful music event in the run up to Christmas, with performances by our voicework group, a local choir "Good in Parts", Centre Manager Alan with Paul and Sylkie Moon. We raised over £600 in just over 4 hours.



They also hosted a display featuring "Owls Out and About", at which we were invited to collect'.

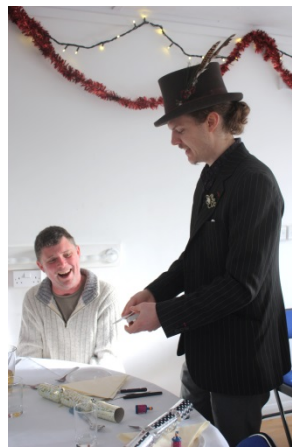
A big thank you to everyone who helped out at both events!



Thank you to all our helpers for a very enjoyable Christmas Lunch!



Volunteers were out in force and showing the Centre off at it's best in December when over 60 were fed, watered and entertained.



New research: Are you a family member or friend who cares for someone with MS?

The EXPERT study, based at Oxford University, wants to hear from you!

The aim of this study is to find out whether carers of people with MS find health information websites useful and how best to provide relevant information online. The researchers are particularly interested in whether online information can help people in a caring role feel more supported. The study will provide useful health information for participants and also inform us how best to provide health information online for carers of people with MS. Participants will be asked to complete some online questionnaires which should take no more than 10 minutes and then look at a website in their own time. We would also like to invite some participants to take part in an interview with one of our researchers.

To take part you must be 18 or over, live in England, have an email address and access to the internet, and help care for someone with MS. If you would like to find out more about this study, please contact Ally Bradley at expert@phc.ox.ac.uk. Please note that enquiring about participation does not commit you in any way.

Burns Night was fun!



Bob Bawtree recited poetry by the bard, and the address to the haggis, music was provided by Centre Manager Alan with Silkie Moon, and food by Jane (the Haggis cooker), Helen (in charge of Tatties and Neaps), and Lin (cranachan expert).

Your MS Specialist Nurses

Brighton	Stephanie Verry	01273 265887	stephanie.verry@nhs.net
	Nadia Abdo	01273 265887	n.abdo@nhs.net
Worthing	Lisa Black*	07768 037088	lisa.black1@nhs.net
Eastbourne	Vicky Lester	07766998037	Victoria.Lester@nhs.net
Chichester & Bognor	Katrina Orchard	07768 145978	katrina.orchard@nhs.net
Horsham	Nadine Morley	01403 227000 ext 7669	nadine.morley@nhs.net
Uckfield	Gill Ferdinands	01825 769999	gill.ferdinands@nhs.net
Haywards Heath	Starting soon		

*Lisa Black will be at the Centre on March 25th and April 29th to offer advice.

Therapies at the Centre

Monday	Hairdressing – Caroline	10am – 2pm (every four weeks)
	Chiropody - Pat	10am – 1pm (every 6 weeks)
	Shiatsu – Heidi - starting soon	11am – 1.15pm
	Drop in Pilates – Norma	1.15pm (1hr)
	Craft Class short courses	11am - 1pm
Tuesday	Aromatherapy Massage - Sophie	10am – 1pm
	Acupuncture - Pippa	10am – 2pm
	Shiatsu - Mary	10am – 1pm
	Physiotherapy - Diane	11.45am – 2.45pm
	Drop in Keep Fit – Lyn	6pm (1hr)
Wednesday	Shiatsu – Charlotte	10am – 2.30pm
	Massage/Reflexology – Mala	11am – 1pm
	Reflexology/IHM-Sonia	10am – 2pm
	Drop in Yoga - Julia	10.30am (90 mins)
	Drop in Tai Chi - Mo	1pm (1hr)
Thursday	Shiatsu – Mary	10.15 – 2pm
	Acupuncture – Pippa	10am – 2.30pm
	IHM*/Reflexology – Sonia	10am - 2.30pm
	Drop in Seated Yoga - Julia	12.00pm (1hr)
	Drop in Pilates – Micci	10.30am (1hr)
	Drop in Keep Fit – Lyn	6pm (1hr)
Friday	Shiatsu - Ian	10am – 2.30pm
	Osteopathy – Virginia	11am – 3pm
	Physiotherapy – Diane	2pm - 2.45pm
	Beauty therapies - Sarah	9.30am – 2.30pm
	Drop in Physiotherapy Gym - Diane	1pm (1hr)
	Drop in Voicework - Rose	11am (1hr)
Everyday	High Dosage Oxygen Therapy – 4 sessions daily Counselling Please ask Alan or Jo for details	
*IHM = Indian Head Massage		
Suggested donations	HDOT £12 for neurological conditions £18 for non-neurological Classes £5	
All individual therapies are £15, to be paid direct to therapist, except physiotherapy which should be paid at reception. Please note: Less than 24 hours' notice may attract a cancellation charge of £5		