

Sussex MS Treatment Centre



01273 594484

Southwick Recreation Ground

Croft Avenue

Southwick

West Sussex

BN42 4AB



- Small Charity- -Big Impact-



Full story on page 12

Charity Number: 801075

Company Registered in England 2319928

OH WE DO LIKE TO **RUN** BESIDE THE SEASIDE



A huge 'thank you' to our [Brighton Half Marathon](#) runners



Patch, Neil, Carla,
Martin (Eggsy), Ros,
Caroline, Jason, Sid, Dani,
Hannah and Robert

Thank you to

PRINTTECH

Nick Stone | Director

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info@printtechprocess.com www.printtechprocess.com

for printing our t-shirts

Manager's comment

Welcome to the Spring edition of the Belle. Despite the unpredictable weather the Centre has been very busy with members enjoying participating in a wide variety of treatments, therapies, classes and social events.

We are really pleased that we have been successful in getting funding and volunteer hours from HSBC to continue the garden project. In April a new patio seating area will be created for all to enjoy. We hope that members will help with the gardening to keep this space tidy for the enjoyment of all.

Funding from sponsored events brings in vital income to the Centre so please encourage friends and family to participate in any of the events highlighted on the back page.

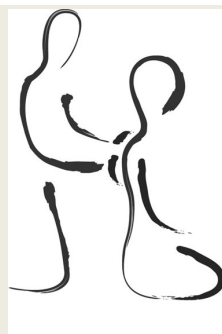
Wishing you all a lovely summer. *Penny*

Introducing

Cat Westwood

While you wait

Seated Shiatsu



15 minute seated treatment. Cat will be offering these treatments on Mondays primarily for partners and carers.

Book a session on the day.

Suggested donation £5

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Introducing



Amanda

Shiatsu

Offering
treatments on
Fridays.

Teresa

**Indian Head
Massage**

Offering treatments
on Tuesdays



Please ring and make an appointment
or book at Reception



About Shift.ms

[Shift.ms](#) is a social network for people with multiple sclerosis. We aim to create a positive, enabling community which powers MSers to acknowledge their MS, rethink how to achieve their ambitions and get on with their lives.

Where Shift.ms came from

Shift.ms was launched in 2009 by George Pepper and Freddie Yauner, following George's diagnosis with MS at the age of 22. MS is the most commonly diagnosed neurological condition in people in their 20s and 30s in the UK. Despite this, George found it difficult to find other MSers of his age, even online.

This frustration led him to set up a website, where MSers could meet and share experiences. This later became www.shift.ms. Find out more about [the team](#) and what we're been up to in [the past year](#).



To achieve the Shift.ms aims, we focus on three areas:

- Reducing isolation and increasing social support for MSers.
- Helping MSers to acknowledge and actively manage their condition.
- Creating a self-sustaining community organisation, run by its members.

Shift.ms believes:

- No MSer should feel alone, particularly straight after diagnosis. We think it's crucial to have support around this time, it's probably the main reason we exist.
- A community can't be a dictatorship. We want to make sure everyone gets a say. Life is interesting because people are different and have different ideas. We respect everyone's opinion and let them speak freely (as long as they're being nice about it, of course).
- Our community is global. Just because we're based in the UK, doesn't mean you have to be.
- Information overload is never a good thing. We love to do innovative projects which help MSers understand their MS in new ways.
- MS doesn't mean giving up your ambitions, just re thinking how to achieve them. We're here to help MSers show each other it's possible.

If you look after someone,
it's important to look after
your own health too!

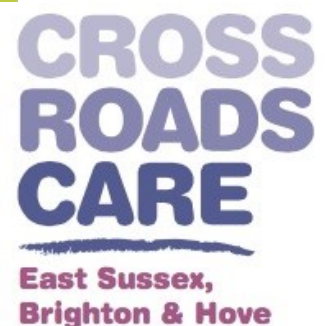
Carers My health matters



This could include cover for you to attend:

- GP appointments
- Hospital appointments
- Dentist appointments
- Optician appointments
- Counselling sessions
- Training courses to support you in your caring role

Crossroads Care can provide support to the person you look after if you feel you cannot leave them alone so that you can attend your own health care appointments.



This service is funded by NHS Brighton & Hove so there is no charge to you, or the person you care for, for this service.

If you need more regular support to leave the person you care for so that you can have a break from caring, Crossroads can discuss the options available to you but there may be a charge.

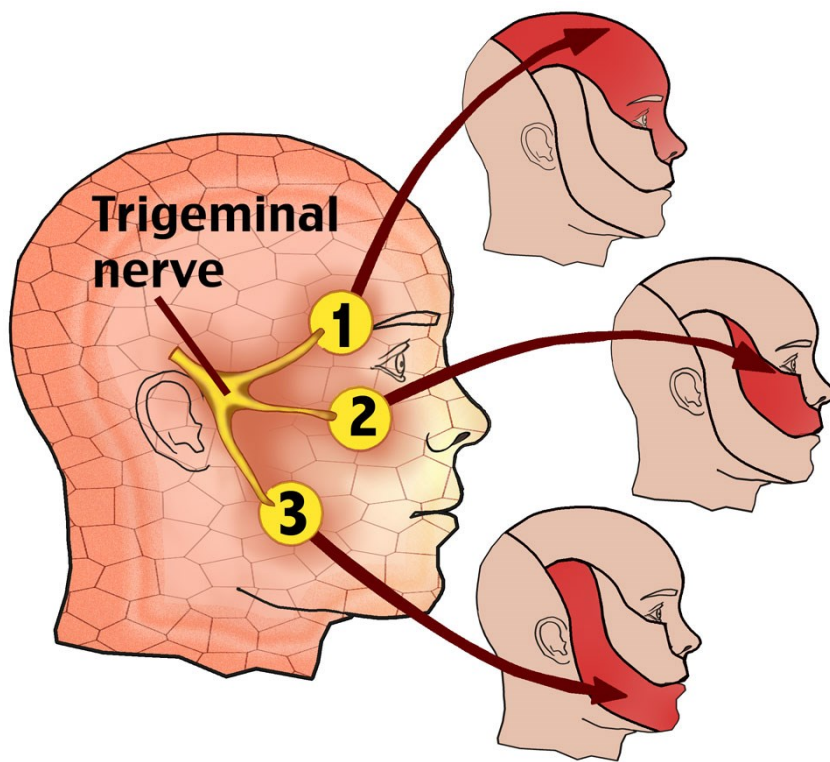
**Contact: Brighton & Hove Crossroads, Community Base,
113 Queens Road, Brighton BN1 3XG**

Telephone: 01273 234021

Email: b&hoffice@esbhcrossroads.org.uk



Trigeminal Neuralgia



Trigeminal Neuralgia is a severe nerve pain which can give stabbing or burning sensations down one side of the face and is often described as electric shock pain. The pain comes on rapidly and can last up to an hour although some people have it for a lot longer.

Research has shown that people who have MS are more likely to experience Trigeminal Neuralgia.

Trigeminal Neuralgia has a huge impact on quality of life and may even cause low mood and depression.

The cause of Trigeminal Neuralgia is still not fully understood but they know there is “cross talk” between nerve and fibres that carry sensations such as touch and vibration to the brain and those that carry sharp pain. In MS this cross talk is caused by loss of myelin on the trigeminal nerve. The damaged nerves react to touch sensations and send incorrect pain signals to the brain.

Using medication can help manage Trigeminal Neuralgia. These drugs would be anti-epileptics especially carbamazepine or oxcarbazepine. They need to be prescribed by a doctor and started on a low dose. These medications do not cure the condition so it is a good idea to stop them when a remission period occurs. In severe cases surgery may be considered.

'NO SHOWS' IN THE DIVE CHAMBER

Please let us know if you are not able to come for your booked dive session. We can then phone people who are waiting for a space rather than have unnecessary empty seats in the Dive Chamber.



ELVIS will be entering the building on

Friday 17th June at 7pm

Tickets: £5 member, £10 member plus carer or £7 non-member.

Stem Cell Research for MS

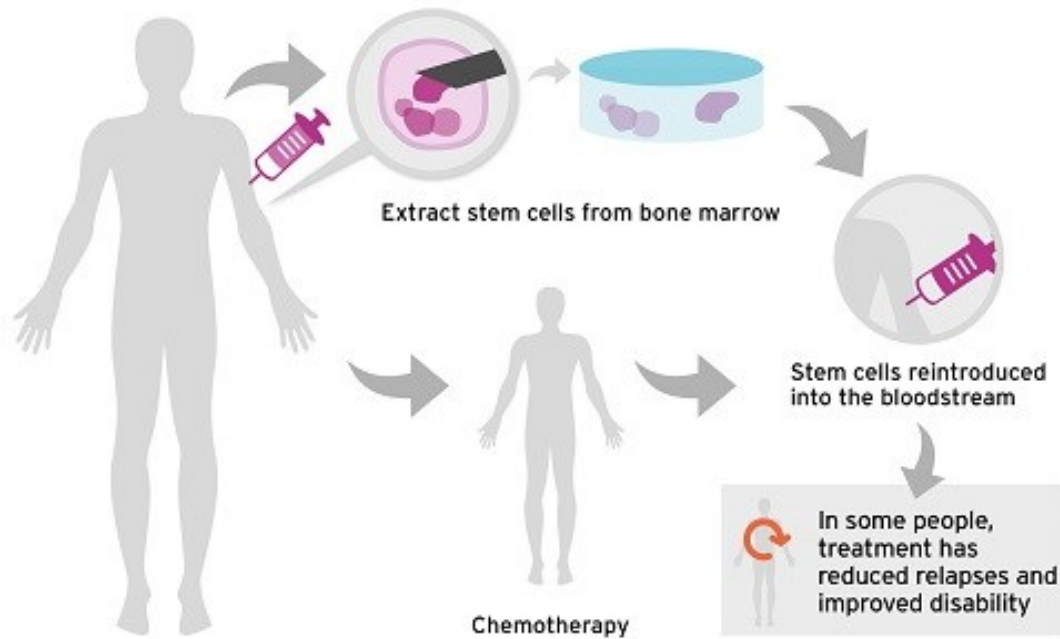


Many of us watched the Panorama programme in January claiming that 'remarkable improvements' had been seen in people with MS after receiving a new treatment involving stem cell transplant.

There is a significant amount of research going on in this field around the world. The trial at Sheffield's [Royal Hallamshire Hospital](#) is part of the MIST trial, a world wide effort to find a cure for MS and a treatment that will repair the damage already done to the nervous system. About 20 patients in Sheffield received bone marrow transplants using their own stem cells which were harvested before receiving chemotherapy to kill off their white blood cells. Most cells in the body can only do one job, for example, a skin cell can never become a brain cell. Stem cells however, have the potential to become other types of cell, such as cells in the muscles, blood or brain so this treatment hopes to reset the immune system to stop it attacking the myelin and use stem cells to repair damage.

Stem Cell Research for MS continued

The process:



A study published last year involving MS patients in Chicago showed significant reductions in neurological disability, and for some the improvements persisted for at least four years, although there was no comparative control group.

The outcome of the more detailed MIST trial - which will report in a couple of years - could determine whether the stem cell transplant becomes a standard NHS treatment for many MS patients.

Dr. Emma Gray, head of clinical trials at UK's MS Society, said: "Ongoing research suggests stem cell treatments such as HSCT could offer hope, and it's clear that in the cases highlighted by Panorama they've had a life-changing impact.

However, trials have found that while HSCT may be able to stabilise or improve disability in some people with MS it may not be effective for all types of the condition."

Dr. Gray said people should be aware it was an "aggressive treatment that comes with significant risks", but called for more research into HSCT so there could be greater understanding of its safety and long term effectiveness.

We will all be following this research as it progresses.

Cream tea and Quiz Sunday 20th

March.

Tickets are now on sale at reception or call the centre to reserve your tickets. £5 member, £10 member plus carer or £7 non-member.





Pippa Hancock BA (Hons), BSc (Hons), MBAaC

Acupuncture is a holistic form of therapy which is part of the traditional Chinese system of medicine. This system believes the body is primarily an energetic organism. If the flow of energy through the body is clear then an individual will be in good health. Illness occurs when the flow of energy is blocked or out of balance. Acupuncture has the potential to manage some of the symptoms of MS and improve levels of wellbeing and quality of life. Many people find acupuncture brings benefit. At the MS Centre low cost treatment is available to people living with MS as well as their carers.

An acupuncture session at the MS Centre lasts about 40 minutes. During an initial consultation questions will be asked about how people are feeling, what their main symptoms are, medical history, medication and so on. The acupuncturist will also look at their tongue and feel the pulse. In Chinese Medicine all of this provides valuable information about the person's state of health. The actual treatment involves inserting needles into specific points. These stay in place for around 20 minutes.

Acupuncture can be beneficial for many of the symptoms of MS. These include fatigue, spasms, as well as urinary issues such as frequency, retention and infections (UTIs). In the case of UTIs antibiotics have been the treatment of choice. However, with increasing resistance of many bacteria to these medicines researchers are starting to explore other options and different approaches used in other societies. This is where acupuncture can be of real benefit. Whilst it can take time to have an effect, especially if someone has a long-term history of infections, many people report reduced frequency of UTIs as well as shorter duration if they do get one. The mechanism by which acupuncture helps with these symptoms is likely down, in part, to its ability to reduce inflammation and pain and so calm bladder irritation.

Pippa Hancock is a qualified acupuncturist registered with the British Acupuncture Council. She has worked at the MS Treatment Centre in Southwick for over five years and has been practicing for 12. She works in Southwick on Tuesdays and Thursdays. You can also find out more about Pippa's work on her website, www.hancockacupuncture.co.uk.

Bingo and Bangers



About 30 people came to this January social event which turned out to be an afternoon of great frivolity and good food. It was delightful to hear Mike Balchin say,

“I haven’t laughed so much in years”!

As usual, thanks to all the volunteers for making it such fun.

[The Cinnamon Trust](http://www.cinnamon.org.uk) has a network of 15,000 volunteers who “hold hands” with owners to provide vital loving care for their pets. For example, they will walk a dog every day for a housebound owner, foster pets when owners need hospital care, fetch the cat food, or even clean out the bird cage, etc. They also have established a national register of nursing homes, residential homes, sheltered housing for the elderly that will accept residents and their pets.

www.cinnamon.org.uk



The Sussex Multiple Sclerosis
Treatment Centre

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MS Information Booklets available on our website

The [MS Society](http://www.mssociety.org.uk) Information booklets are available in hard copy form at the Sussex MS Treatment Centre but we are providing links on our website so you can download the latest version from the MS Society. Many of the booklets are also available as audio downloads. They can be found under the ‘Home’ page tab under ‘Information Booklets’. For those of you that receive the Belle electronically, please follow the link. http://mssussex.com/?page_id=1701



The Building Project Update

Whilst everything carries on as normal at the Centre, we've been busy in the background continuing to investigate upgrading our Centre to make it even better.

Although we are all very fond of our prefabs, the current building doesn't allow us to develop and presents a lot of challenges such as our inaccessible kitchen, poor circulation space and overcrowding. Also, as it ages, it is becoming more costly and difficult to maintain.

Our aim is to remain on our current site which will of course present some logistic challenges, but we are determined to plan it so that disruption is at a minimum. If, which at the moment seems unlikely, we look for another site it will be because it gives us more space and allows us to keep the current Centre open whilst building work takes place. We will only contemplate sites that are easily accessible by public transport.

This is your centre and we would be delighted to receive your comments on this project, expressing concerns or making suggestions. There is a 'Building Project' comment book in reception (light blue with white spots), you can speak to staff or trustees, or email jane.taylor@mssussex.com. We have put together a comprehensive design brief using the experience of staff, Trustees and Centre members and have visited a number of other MS Centres that have completed rebuilds to learn from their experiences. On a recent visit to [Kent MS Therapy Centre](#) all the members questioned commented that although it is stressful, it is absolutely worth it in the long run!

We have recently appointed Martin Green from [MG Architects](#). We felt he really understood what our Centre means to us and he was quick to realise the importance of continuity of service and keeping the welcoming community feel, not turning it into a 'clinic'. Martin will take us through the early stages of our feasibility study, helping us assess what is possible and achievable. As we progress, we will be setting up some member focus groups, so if you'd like to be involved let us know.

Finally, we are estimating the whole project will cost over £1,000,000! This will mean a big fundraising drive and is most definitely achievable. We need a name for the appeal (Kent MS Therapy Centre called theirs The Butterfly Appeal). Any suggestions are welcome! We'll be holding a ballot to pick the winner.



Making it happen

From the front cover. The story so far.



The wheelchair adaptation project began last year when one member wanted to produce something for our 'Art for All' exhibition. We had ideas about painting the wheels on his wheelchair and for him to make marks riding across some paper, printing and overlaying the tyre marks on to acetate and from those images create a mobile but this seemed to be taking the making physical art further and further away from the artist. We searched 'wheelchair art' on the internet and found a film clip showing a wheelchair attachment that dispensed paint through a funnel directly onto canvas. We looked into whether it was something we could buy from a manufacturer but this proved difficult as many of the tools were created across the Atlantic.

Making things possible

We contacted [Remap](#), a charity that custom-makes equipment to help disabled people live more independent lives. One of Remap's Occupational therapists, Sara McLafferty visited the Centre to find out the kind of equipment we were looking for and took our request to Remap's next committee meeting where it was taken up as a case. Remap have connections with [Brighton University](#) through one of their retired engineers and we were delighted to be contacted by a team of 2nd year Product Design students, who have a design collective called [The Process](#), who wanted to get involved with this project. They visited the Centre to see the type of device needed and two weeks later they had a prototype to test. The results, created by Barry, can be seen on the Gym wall. The students continue to work on this exciting project.



Would you like to see Brighton & Hove Albion play?

Not a season ticket holder but would like to see [Brighton Hove Albion](#) play at the Amex? We can help.

Dominic and myself went on a tour of the Amex showing the amazing facilities and ease of access for disabled supporters.

We were shocked to hear that at 99% of matches there are spare tickets making it almost possible for a disabled supporter to go to your chosen match.

There are 175 wheelchair spaces and large changing rooms with hoists although the straps are not provided. They also cater for Deaf and Hard of Hearing and Blind or Visually Impaired supporters.

If you are receiving DLA, PIP, AA, or SDA then you will be able to get a ticket and your carer will get in free. Proof of these need to be shown before the match day. We also have information on travel and parking.

If you would like any help or information please contact Nikki at the centre or email me at social.mssussex@gmail.com



ART FOR ALL WORKSHOP

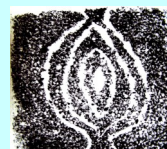
SATURDAY 7TH MAY

10AM-4PM

SUGGESTED DONATION £5



Come and join us for all
or part of the day.





Two members holiday experience in disability friendly cottage

We spent a week in Norfolk at the [Norfolk Disability Friendly Cottages](http://www.nd-fc.co.uk/) which are located a short distance from Kings Lynn. We rented the “Crew Yard” cottage which is a two-bed accommodation with very good disability facilities and an excellent wheel-in shower room. The views from many of the cottages are very beautiful.

It is a family run business run by Lavinia King and providing 8 self-catering cottages designed to accommodate the disabled and their family and friends. The cottages are suitable for everybody, disabled and able bodied alike. It is situated on a converted farmyard on the outskirts of the quiet village of Bircham and about five miles from the Royal Estate at Sandringham and seven miles from the North Norfolk Coast. It is in an area of natural beauty but of course you need a car to get about.

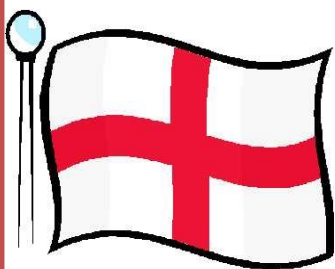
Christopher Fox-Walker

We have also been here twice. Once in the Crew Yard and also in the Little Workshop. The accommodation is excellent. The owner Lavinia was a nurse and dedicated to ensuring you have a great holiday.

You are able to get WiFi at an added cost of about £15 a week but to be honest signal was very weak. Both Dom and I can highly recommend these facilities.

Nikki Manchee

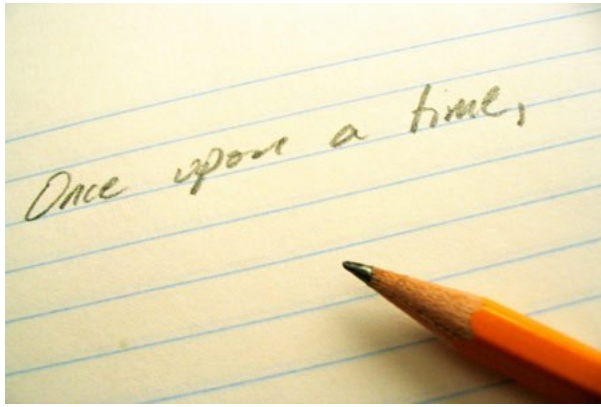
Their website is: <http://www.nd-fc.co.uk/>



St George's Day Party Friday 22nd April at 7pm.

Come along and enjoy a really good old sing song and a fish and chip supper.

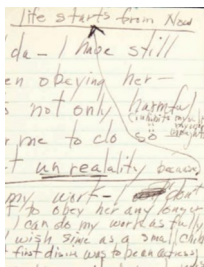
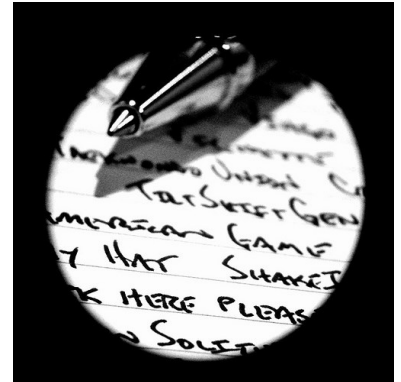
Tickets will be £5 member, £10 member plus Carer or £7 non member.



They 'Kick Started' their writing with Chris Sanders

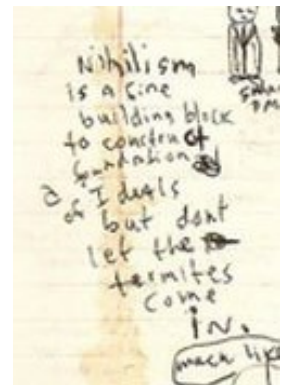
On Saturday 13th February Chris held a creative writing workshop here at The Centre and the following are some comments from the morning.

'I found today's creative writing taster session really enjoyable and I was so surprised at how I was able to do the tasks with enjoyment and confidence. I was nervous beforehand but I need not have been! We were all in the same boat! I recommend this workshop/ course to anyone and don't worry if you have not had much contact with books or reading.'



'As the day drew near to the 'Introduction to Creative' Writing I began to feel very nervous. Many thoughts went through my mind the main one being 'Would everyone be using BIG WORDS'? I am not the type of person to use big words so I almost cancelled.'

'I was not sure what to expect from the recent creative writing workshop but found it very enjoyable. Chris's enthusiasm shone through and made it a lovely, relaxed and informative morning. The little exercises brought out imagination and humour; I felt I learned a lot not just about writing but also myself. Yes, I will definitely be back for more.'



'All in all it was a great morning and the time went too quickly. I look forward to doing some more of these classes as I found them relaxing, fun and doing something different for myself.'

We are hoping to hold a few more Creative Writing workshops after Easter on a regular basis but need more participants. If you would like to give it a try, please keep an eye out for diary events on our website or contact the Centre.





The Sussex Multiple Sclerosis Treatment Centre

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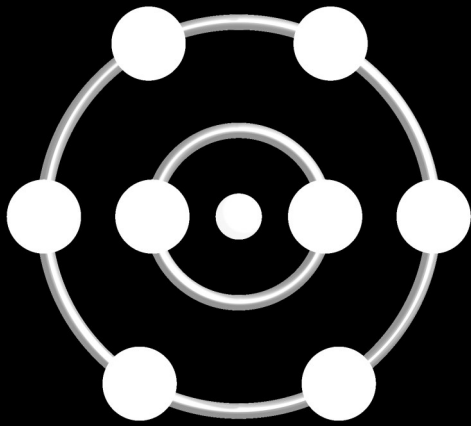
Therapies

Contact Us



Details of all our fundraising, social and workshop events can be found on our website diary.

If you would like to take part in or volunteer to help with any of our fundraising events, please contact the Centre on 01273 594484



Make Tracks.

Fundraising Bike Ride 22 miles

22.05.16



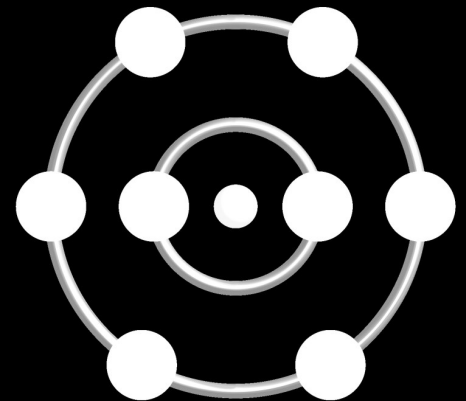
Peacehaven Heights

Don't hang about.

Fundraising Abseil

115ft

18.09.16



Our Local Charity Partnership with Sainsbury's, West Hove will be ending at the end of April. We have the opportunity to hold 3 fundraising events. Can you help with any of the below?

Friday 29.04.16 Tombola and bucket collection

Saturday 30.04.16 Pete cycling and 'Crazy Jain' singing

Sunday 01.05.16 ??? IDEAS NEEDED