

Heads Up

THE NEWSLETTER OF HEADWAY HURSTWOOD PARK



ISSUE: SUMMER 2012



A word from the Chair

Appointment of our new CEO

I am delighted to announce that we have appointed Michele Fleming as our new Chief Executive Officer. Michele takes up the post on 2 July 2012. (She has written an article for this edition of "Heads Up").

We had a significant number of applicants for the post, and the competition was fierce. Michele was our first choice and we are very pleased that she is joining us.

Michele not only brings with her to Headway many years of experience as a senior occupational therapist but also considerable management experience. Up until joining us Michele held a senior post within the NHS as Head of Allied Professionals at East Sussex Healthcare NHS Trust. Furthermore, as many of you will recall, up to the end of last year, Michele was also a Trustee of Headway Hurstwood Park. Therefore, she already has an in-depth knowledge of the workings of the Charity. This means that she doesn't have to have a standing start.

The appointment of Michele is an exciting moment for the Charity. This is a new chapter. For my part I am really looking forward to working with Michele in developing and strengthening the work of the Charity.

The Future

With the appointment of the new CEO the Trustees are taking the opportunity to review the work of the Charity and the way in which we operate. It is very important that we stand back, from time to time, and take a long term strategic view so that we can ensure that the Charity is not only sustainable but flourishes.

Michele and others will be undertaking extensive market research as to what our stakeholders require from us and, at the same time, will look into other sources of work and funds for the Charity. This research will lead into a strategy meeting which we are holding at the end of September 2012 to plan for the future. We will be inviting the views of the staff and volunteers as well as our funders.

Thank You

I would also like to acknowledge and thank publicly the management team, the staff and volunteers for their work over the last few months between permanent CEOs. I, and the other Trustees, have been really impressed by everyone's hard work and commitment during this period. I appreciate that it probably hasn't been easy for those concerned. However, everybody has worked extremely efficiently as a team which, I believe, reflects well on everyone involved at Headway.

I would particularly like to thank Wendy Pengelly, who stood in as our manager, and also the senior management team, Lisa, Georgina, Jane and Ingrid. I realise there are many other unsung heroes as well!

Fundraising

As you know, we are trying to improve our charitable fundraising. The staff and volunteers have really taken this on board. They have formed a very effective fundraising group and are getting involved in all sorts of exciting activities.

One of the most impressive, over recent weeks, was the "Yard Sale" which took place at Headway House on Saturday, 12 May 2012. Fortunately it was one of the very few sunny days we've had this summer and there was a large turnout. I have to say that the items on sale were probably not what you might see at a sale at Sotheby's but this makes the significant amount of money raised even more impressive.

Staff and volunteers turned up to run the day in their spare time. There was a jolly and vibrant atmosphere. Not only did it raise money but it gave us an opportunity to show-off the centre and our work to members of the public.

Thank you to all of you who took part.

And Finally...

I am writing this on yet another grey, cold, windy "summer's day" and sincerely hope that we really do see some summer weather sooner or later.

On that note, I still look forward to seeing some of you at this year's Summer BBQ scheduled for Saturday 4 August 2012, and fingers crossed for fine weather on that day!

Wishing you all well over the summer.

Francis Lacy Scott

Chair

Introducing Michele Fleming, the new CEO



I am very pleased to have this opportunity to tell you a little bit about myself. I have over 25 years experience working in health, social care, the private and voluntary sector and have held management and professional leadership roles leading multidisciplinary teams

of therapists, nurses and support workers. I am an occupational therapist by qualification and my clinical role has mainly been provision of rehabilitation to adults with a range of physical disabilities in community settings including people's own homes.

You may be aware that I was recently a Trustee of Headway Hurstwood Park which gave me an excellent opportunity to learn more about the charity and what it has to offer. As you know HHP's mission is to promote an understanding of acquired brain injury and to provide care, support and rehabilitation to people affected by it. These aims are shared by the occupational therapy profession and throughout my career I have strived to enable my patients to achieve maximum independence and to feel empowered to make choices about the way they live their lives.

Last year I also supervised two occupational therapy students who were on placement at HHP which enabled me to work closely with some of the team. I found everyone I met to be committed, motivated and energetic and as I take up my role as Chief Executive I am delighted to know that I will be working with such an enthusiastic and experienced team.

There is a lot of excellent work going on at HHP which gives a strong foundation to build on and to promote the charity as a leading rehabilitation service for people with acquired brain injury. Over the next few weeks I plan to work with the team and the Trustees to look at how we can grow the organisation so we can continue to provide a high quality service and support more people in the county with ABI.

I live in East Sussex with my family and outside of work I enjoy gardening, walking, swimming and the theatre. I am also in my final year of a part time course at Canterbury University studying for an MA in Management Studies.

I look forward very much to joining Headway Hurstwood Park on 2nd July.

With best wishes.

Michele

CEO

Centre Update

Hello Everyone.

With the weather being so poor we set to “spring cleaning” Headway, from the attics to the outbuildings. In the process we rediscovered many boxes of forgotten ‘stuff’, which encouraged us to put on a sale.

The weather continued to be a wash out, so much so that days before we were wondering if we would have to cancel. Thankfully the sun came out the day before and stayed out for the sale.

We were unsure what to expect as this was the first fundraising event for a number of years! We had a good turnout, many clients and families supporting the day. We sold mostly bric a brac, crafts and pottery. The woodwork group had made planters and bird tables which proved very popular and the teas and cakes were a great success.

So a big thank you to all the clients, volunteers, staff and buyers who made it possible for us to raise the grand sum of £492, which we were delighted with.

The sale started the week for ‘Hats for Headway’ with Friday 18th being the day to wear your hat. Lindfield School also supported us on this day with the pupils making a donation to wear a hat and by doing so they raised £225.60! So another big thank you to all those involved.

amount on offer. Then, after hearing a conversation in his local, Brandon from Black Forestry, offered not only his trucks but also his men to collect, load up and deliver to Headway. It appears Brandon’s father had an ABI and at one time attended Headway so was happy to help us. Many thanks to both him and his team for making the job so straight forward.



As you can see we have had quite a busy time and look forward to organising future events as good fun was had by all. So, please, if you have any ideas or would like to help out in the future we would love to hear from you.



Finally the woodwork group is thriving with plenty of ideas and enthusiasm. We have been very lucky to have been given wood from Burnside Daycentre which sadly had to close. The wood had been donated to them by Alexander Rose and we just had to pick it up. This looked a difficult task at first, finding a large enough vehicle to collect the



Best wishes

Fiona McHugh

Day Leader

Bowling in Brighton

As the last session of the photography group on a Wednesday a trip was planned to the bowlplex in Brighton Marina. The clients were very excited and keen to let their hair down. It took us quite a while to get through Brighton though as the traffic was as thick as it always is. We headed straight into the bowlplex and had a great game.

We were all in good spirits and saw some fantastic spares and strikes from all the clients. After the clients were finished, winning by a substantial lead, it was time to have some lunch. This didn't go quite so swimmingly as the

rest of the day. Half of us received our food in next to no time but unfortunately half the group ended up eating their lunches on the journey back to Newick.

The trip back was a lot quicker with next to no hold ups on the road. Pulling up back at Headway the weather took a turn for the worse and the thunder and lightning was fabulously loud.

The trip was perfect to get us out of the centre and to have an opportunity to go out into the community and the clients thoroughly enjoyed it.



Jubilee Celebrations

As part of the Jubilee Celebrations the 'Papier Mache' group made this fabulous regal Lion and Unicorn. They took about eight weeks to make and all the group members had a finger in the glue (so to speak). They made, together with bunting also made by the clients, a very impressive sight when put on display in the reception area of Headway House.



The Headway Potters

The 'Potters' at work...



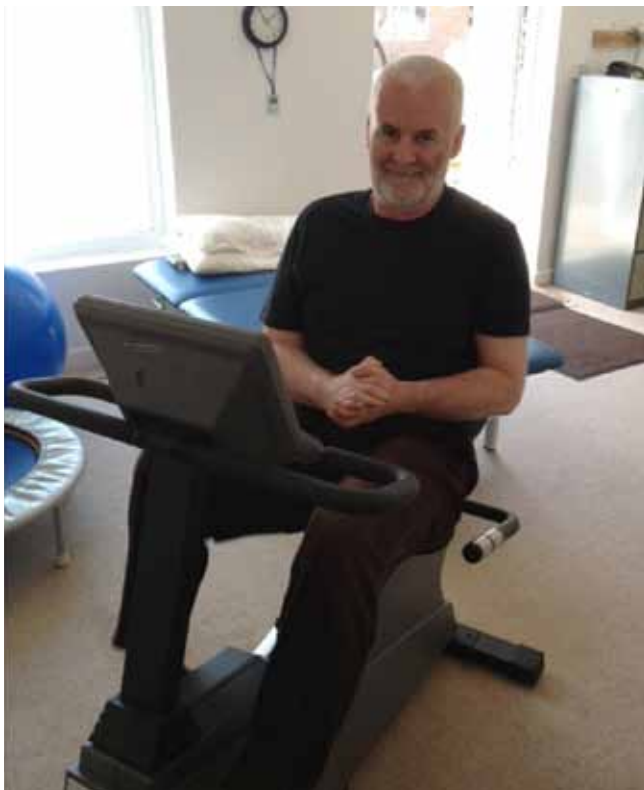
... and the finished articles



Headway Gym

Headway gym is now open 5 days a week to clients attending Headway. Hours are 10am – 2.30pm every day apart from Thursday which is 10am – 12.30pm. Julia Buck, neuro physiotherapist, is now available one day a week at Headway to provide assessments and review of gym clients as well as rehabilitation advice.

Phil Saltmarsh has been working alongside Julia in the gym for the last year as a personal trainer level 3. Feedback has been extremely positive from both clients and staff that having this combination is really moving the clients' rehabilitation and fitness forward.



Roger

Roger has been attending the gym since April last year and over that period of time has been having 2- 3 sessions. During this time he has made great progress in his cardiovascular fitness and improvement in his strength and movement. There has also been the opportunity for his local physiotherapist to come and work with Julia and Phil to ensure consistency in his rehabilitation.

Andy who has been attending Headway gym for 5 years twice a week comments 'he has managed to do better exercises which are more controlled and defined under Phil's supervision. I look forward to attending the gym and have even started getting to the gym on time. Phil is a great instructor and keeps me motivated!'

Headway have made the decision that the gym will be the next area for development and will be exploring fund raising opportunities to ensure that this can occur.

So if you want to come and use the gym let one of the staff at Headway know and we can organise an assessment for you.

Volunteer Spotlight



Hello everyone,

Nothing to report on the 'volunteer front' this edition – see you next time.

Ingrid

Ingrid Giovani

(Volunteer Coordinator)

Message from the Company Secretary

Firstly, thank you for bearing with us on the telephone front. What a nightmare this new technology has been. We want to have options available so that Lisa and Georgina can use the technology to divert their calls to their mobiles when they are not in the office. However, this has given us problems with where the telephones are ringing in the building so that everyone thinks the call is not for them! We have spoken to BT and are about to change to the setup of the system. It may even have happened by the time this newsletter comes out.

Secondly, as you will have seen we have had a busy few months on the fund raising front. Fiona has already reported on the Spring Yard sale, which was at the beginning of Action for Brain Injury Week. Friday 18th May was 'Hats for Headway Day' and we made a small collection at the centre with an array of hats being worn. We were all very taken with Francis Lacy Scott's' fishing cap! Lindfield Primary school took part as well raising £225.60 for us so thanks to all the staff and children for joining in the fun.

Thanks also, to Maureen Rae who raised money for us by running the London Marathon. She raised £333 for us.



Maureen Rae

Finally, we are all looking forward to welcoming Michele to Headway Hurstwood Park and hope she has had a good holiday in France so that she arrives fit for anything we throw at her (not literally!).

Wendy Pengelly

Community Support and Information



Hi Everyone,

I am the Community Support Manager and my role is primarily to receive referrals to HHP from anyone affected by acquired brain injury and to provide emotional support, practical advice, and signposting to other relevant agencies. This includes referring people to Social Services to apply for funding for the centre, satellite service and outreach if required. As well as this I am responsible for co-coordinating our support groups and counselling service and am regularly involved in providing presentations/education sessions to raise awareness about acquired brain injury.

Lisa Wickham Community Support Manager

Support Groups

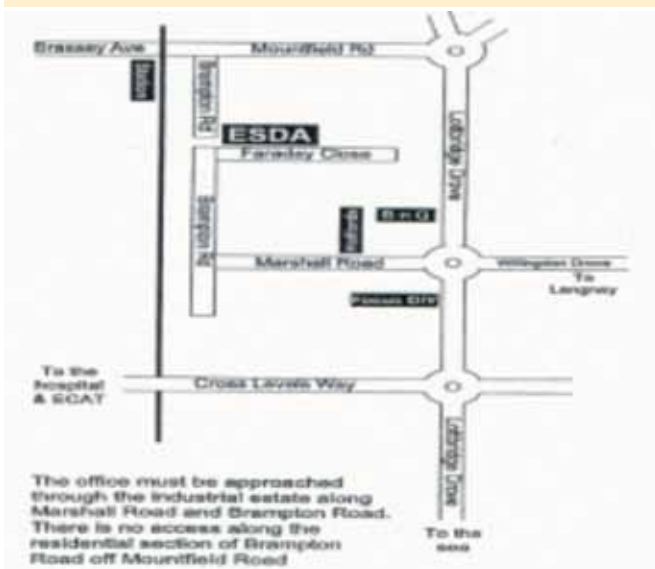
We have two support groups running each month (excluding August) which aim to provide everyone affected with the opportunity to meet people in similar situations; to obtain and exchange information and support from facilitators, speakers and each other in an informal setting. Often new friendships are developed providing an on-going source of support

Eastbourne Support Group

Date: 1st Wednesday of the month –
4th July, 5th Sept, 3rd Oct (no meeting in August)

Time: 7.30-9.30pm

Address: East Sussex Disability Association,
1 Faraday Close, Hampden Park, Eastbourne BN22 9BH

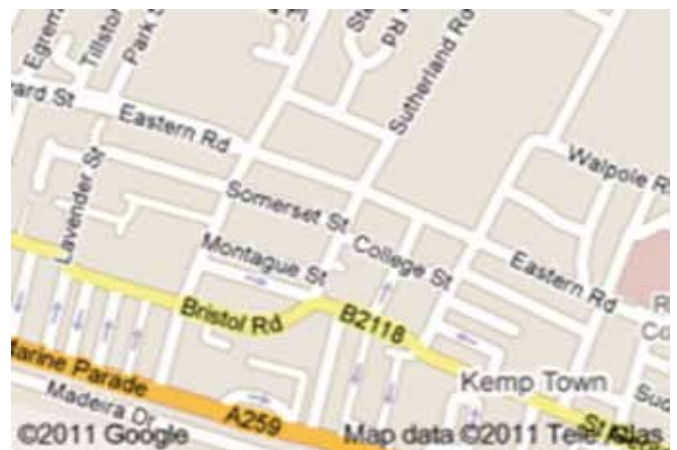


Brighton Support Group

Date: 3rd Thursday of the month –
19th July, 20th Sept, 18th Oct (no meeting in August)

Time: 7.00-9.00pm

Address: Low Vision Clinic, Montague House,
Montague Place, Brighton, BN1 1JE



The meeting takes place in the Low Vision Clinic which is around the corner from the main car park entrance in Somerset Street opposite Evelyn Genie Court; The Stag Pub is on the corner of Somerset Street.

How to get to the venue:

- Buses: 1, 1A, 1B, 2, 2A, 7, 14B, 14C, 25C, 40X, 81, 81A, 81B, 8K, all stop by Gala Bingo Hall on Edward Street. Montague Place is a short walk from here.
- Buses 37, 37B, 47, 52, 57 all stop on Bristol Road/St Georges Road.

Counselling Service

We have a counselling service open to anyone affected by ABI. Sessions can take place at Headway, Montague House in Brighton or East Sussex Disability Association in Eastbourne. The therapists that provide the counselling are trainees and are on placement with us. Sessions are confidential and aim to give people the chance to talk about their feelings / experiences in a one-to-one setting. **Contact Lisa if you would like to find out more.**

August BBQ

Please see the form below regarding this year's BBQ. It will be lovely if you can come along. Please let me know ASAP if you plan to attend so we ensure we have enough food on the day!

If you would like to discuss the community support service further please contact me on 01825 724343 and press option1, or by email headway_lisa@yahoo.co.uk

Bye for Now

I also wanted to let you all know that this will be the last

time for a while that I will be writing in the newsletter as I am expecting a baby on 24thSep and will be on maternity leave from end of August, early September.

We haven't sorted out who will be covering my role yet, but I didn't want to leave without saying goodbye (temporarily). I will let the staff at Headway know when my new addition arrives and I'm sure they can let you all know.

Take care

Lisa

We would like to congratulate Lisa on her very good news and send her our best wishes for the future. She may find the work of a Community Support Manager is a lot easier than being a Mum which can be the hardest but is the most rewarding job of all.

Headway Hurstwood Park Summer Barbecue

Saturday 4th August 2012, 12.30 - 3.30pm



(Names).....

Will be attending Headway Hurstwood Park Summer Barbecue on Saturday 4th August at Headway House, Jackies Lane, Newick.

There will be adults in my party and children.

	Adult	Child
Number of 'meat' meals required
Number of vegetarian meals required
Cost - £5 per person		
My telephone number is.....		

We would prefer to receive payment before the BBQ, so if you are sending a cheque, please make it payable to Headway Hurstwood Park. However, if this is not possible please bring the correct amount with you on the day.

Please complete and return this form to Lisa Wickham, Headway Hurstwood Park, Jackies Lane, Newick, East Sussex, BN8 4QX no later than the 20th July 2012. Alternatively you can e-mail your details to Lisa at headway_lisa@yahoo.co.uk or call 01825 724323.

Person Centred Support

Georgina Baker (Outreach Manager)



Hello Everyone,

Thank you to those that have given some input / feedback of what they would like to see from the outreach section – we will be working on these.

A few things happening at Headway...

- A big Goodbye to Kate Roberts who left at the end of April, we all hope she is having an amazing experience surfing around Costa Rica!
- Thanks and goodbye are in order as Jamie Bragan, one of my social work students, who completed the Outreach and Montague satisfaction survey during his 100 days of placement - *best of luck for your future!*
- I am not sure if you will remember Tracey Kissane, my student from last year? I have great news that she is now a qualified social worker so we may work with her again in the future!
- Leanne Thomson has changed from a Centre Day Leader to the Outreach Day Leader – the clients that have Outreach have been informed but I would like everyone to know she is now another contact for the outreach service.
- Did anyone complete the 'wordsearch' in the last issue? Feedback on whether you would like similar things included in the newsletter would be great.

I hope we get to see some more sunshine in the next 3 months!

Best Wishes

Georgina

Montague House

The following is an account from one of our clients and how he feels Headway support has improved his life. Gary has received support initially from the Community Support Service, then Outreach and now also attends Montague House once a week.

This is a true quote from Gary...

"If you have a brain Injury find Headway. If you are in care do not worry Headway support staff are not carer morons they work hard to make a real difference to your life, they work hard on the things you want and need, not just the easiest things that can be found. They can help you to understand what has happened and ways to improve; learn again or another way. After health service waste of time waffle I was astounded and pleased at last, some honest true advice. No one promises, but you can work to make your life acceptable to yourself and others."

News Update

Hospital Redevelopment – Local Support and National Progress



On the 27th January, Brighton and Hove City Council's Planning Committee gave the go ahead for the redevelopment of the Royal Sussex County Hospital (RSCH). This was a key step for the programme and for the Neurosciences Centre, as it will move to a new, significantly improved facility as part of the redevelopment. The Neuroscience Centre will be in the first of two new buildings planned for the RSCH main site, currently scheduled to start taking patients in 2017.

After the unanimous decision of the Planning Committee it might seem that everything has gone quiet with the redevelopment, but nothing could be further from the truth. The granting of planning permission allowed the redevelopment business case to be considered by regional and national NHS bodies. In March, NHS South of England approved the business case and at the time of writing the redevelopment team are working with the Department of Health and The Treasury to secure the release of funds for the programme as soon as possible.

If everything goes according to plan, preparation works on the RSCH site will begin later this year. This will include preliminary works for two temporary buildings where some services will go during construction works and preparatory work for the Helipad on top of the Thomas Kemp Tower.

In terms of Neurosciences the redevelopment will provide an essential expansion, doubling the number of neurosurgical beds, giving a three fold increase in neurology beds and setting up both an additional theatre and new, bespoke facilities for day care. The move to the Royal Sussex County Hospitals campus will allow the neurosciences team to work more closely with other key specialist services including cancer, trauma and imaging. This will improve services for many patients and remove the need to send the most severe trauma cases, those involving combined head and body injuries, to Southampton or London.

For more information please visit the website or contact the redevelopment team as detailed below.

Website: www.bsuh.nhs.uk/3ts
E-Mail: hospital.redevelopment@bsuh.nhs.uk
Address: 3Ts, Royal Sussex County Hospital,
Sussex House, Abbey Road, Brighton,
BN2 1ES

Richard Beard 3Ts Head of Communication and
Engagement

Items of Interest / Discussion

The working life of a Headway UK Regional Co-Ordinator

Based on the South Coast – and working from home – I cover 7 Counties across the South East. Within that area there are 13 Headway groups (all independent but affiliated organisations) and 1 Headway Branch – not independent of Headway UK but having its own Committee and a range of activities provided to its members by volunteers.

I am often asked “what do you actually do”? And although I am not often lost for words, on these occasions I am never sure where to start! Every day for me is different – a typical diary entry for a working week could be visiting a HW group 100 miles away, attend an AGM and an ABI forum, meet with a Commissioner, prepare for a workshop or type up notes of a meeting!

Sometimes, I have the luxury of spending time in my office overlooking the harbour and sea which gives me great joy – and I am fortunate to enjoy such a nice working environment with my dog by my side.

On days when I am not in my office my work can be very diverse as the above diary extract shows. I spend considerable time supporting the HW groups in my area, particularly those who have less staff or are going through difficulties. I could be assisting them with recruiting Trustees, providing support and guidance to the Manager or attending Board meetings to give an overview of what is happening across the South East. Sometimes I will run workshops for staff and volunteers.

I also facilitate three Regional Forums a year – where groups come together to share the challenges and positives of their work. This is a great opportunity for networking and many find it encouraging to know that other groups may be facing the same difficulties and to exchange ideas on how to overcome these difficulties. We also focus on the sharing of good practice and achievements.

In order to be able to do my job properly, it is necessary for me to keep up to date with new legislation and guidance. Anything that will affect Headway from social care reforms to new Charity Commission guidance. While I do not pretend to remember it all – I will know where to access information!

My work can be challenging at times but largely I enjoy it tremendously, meet lots of really good and committed people and work with a great team of colleagues who are spread across the UK. I also have an opportunity to be involved in things that I am particularly interested in – such as facilitating workshops and networking. I recently attended a session on a Health and Criminal Justice pilot which I am particularly keen on being involved in more. As many of you will know some of the implications of ABI can often lead to behaviours which may find somebody in front of a Magistrate. This initiative aims to try and prevent that by early intervention and diversion. Having spent many years working in youth offending and particularly diversionary schemes – it is like going home!

At the end of a long day – I come home to check my emails, making sure they are all acknowledged even if I can't action them straight away. Thankfully I am quite organised and have a policy of good communication so unless it slips through the net inadvertently your email message to me will be answered hastily!

If you would like to contact me please email me on se.regional.co-ordinator@headway.org.uk

I look forward to hearing from you!

Best wishes to all

Rikki Gandolf

A Message from Headway UK

Colleagues

I am pleased to announce that double Olympic gold medallist, James Cracknell, has agreed to become Vice President of Headway UK. Since sustaining his brain injury in July 2010, James and his wife Bev have made outstanding efforts to raise awareness of Headway and their support is much appreciated.

James' office has requested that any communication from Headway Groups should be channelled through Headway UK. Please forward any communication to me and I will liaise directly with his office.

Best wishes

Peter McCabe Chief Executive

LIFE ON THE ISLE OF WIGHT (part 2 of Ann's story)

Dear Reader

Over the last few years I have not been able to visit Headway Hurstwood Park as often as I would have liked but hopefully this will change in the near future and I look forward to meeting many of you on my trips to the 'north island' as we islanders call the mainland.

In 2007 I moved to the Isle of Wight with John my husband and Ian our son. We had been regular visitors to the island for well over 40 years (am I really that old) and had a holiday caravan here for 13 years. We always loved the island for its peace, tranquillity and general slow pace of life.

As a family we absolutely adore living here and would not swap it for the world. The only downside being that my daughter still lives on the mainland and we don't get to see her as often as we would like. She and her partner would join us tomorrow if they could but employment opportunities here are dire and as they both have very good jobs on the mainland they feel it prudent to stay where they are.

As I write this article, not only are private gardens full of colourful daffodils and blossom trees, each road and lane we travel is lined with spring colour. Being an island we miss out on a lot of the cold, snowy weather. For instance we didn't get any of the snow earlier this year that we know you experienced.

If you want to 'go back in time' by about 20 years I can recommend a visit here for a day trip or if you can a longer stay. When you go into a shop and the conversation is about the weather don't expect to be served until they have finished the monthly outlook – this is one of the things you have to get used to when living here. After moving into our house we had to have it completely re-wired and re-plumbed and I remember one of the electricians telling us that the one word we will have to get used to living here is '*mañana*' - on the island it doesn't mean '*tomorrow*' it means 'sometime' – I think this sums up life here perfectly!

In 2008 I joined the local branch of Headway, in 2009 became their acting Chairman and then Chairman. I do sometimes wonder if I was 'under the influence' of drink, drugs or rock'n'roll at the time. Ian reckons it could have been all three!

On the Isle of Wight, as in many other parts of the country, acquired brain injury is often seen as the 'forgotten' disability. I believe this is because it can be a very expensive and long term problem and therefore nobody accepts the responsibility. It is only with the hard work and diligence of Headway staff and volunteers that services for survivors of head injury are being addressed.

There have never been specialist facilities for survivors of an acquired brain injury – no acute or secondary rehabilitation, no Headway House and no on-going support apart from that offered by a Headway support group. Over the past 18 months the committee have been lobbying our PCT to provide these facilities including a Headway House that we feel our members both need and deserve. Although they have suggested two venues during the last year nothing definite has been forthcoming and we are now being forced to look at the private and other charity sector. We have considered trying to raise £500,000 to buy and equip our own bungalow but being a small island with limited resources fundraising in the present economic climate is extremely hard. Having said that, we have had wonderful support from local businesses, individuals and the Rotary Clubs for which we are extremely grateful. We attend as many fairs and as other events as possible to raise both funds and awareness. The support we have been given and the events we have attended enable us to further enhance the activities we offer our members.

On the island there are an estimated 1,250 people living with the effects of an acquired brain injury and we have been trying to raise awareness of the services that we can offer at our support group meetings.

Over the last 18 months we have become 'victims of our own success' – just like we did at Headway Hurstwood Park all those years ago. Our attendance at the Support Group has grown from an average of 4-6 a month to now over 30. Just over a year ago we introduced activity sessions at our meetings and this January we introduced a monthly 'social outing'. The only socialising for some of our members is the evenings they have out with Headway so we feel this is a most important facility that we can offer.

I hope you enjoyed reading my history of Headway Hurstwood Park in the last edition of 'Heads Up' and now about Headway Isle of Wight.

Finally, I ask you to raise a glass to the continuing growth and success of Headway Hurstwood Park, Headway Isle of Wight and the Headway organisation as a whole for the help and support they all show to the survivors of acquired brain injury.

Thank you for reading my story.

Ann Cummings

Client's Voice

All contributions from the clients are in their own words and have not been amended in any way.

THE ADDICT

A poison mass of frenzied veins

His stomach lurched, as he's sick again.

His grey eyes filled with pain & fear

Sitting in a corner he knows the end is near.

People pass, but no second looks, cause they've seen the telly & read all the books.

And finally he breaks down & starts to weep

And he closes his eyes for his final sleep.

Dead - he was an addict.

OUTREACH

On one of my Outreach sessions we went to visit Charleston House, the well known and historical home & country meeting place of the writers painters & intellectuals who in bygone days were known as The Bloomsbury set.

The interior was painted by the artists Duncan Grant & Vanessa Bell and together with their collections form a unique example of their decorative style.

Their unconventional lifestyle drew other like-minded people together such as Virginia & Leonard Woolf & EM Forster, Picasso was also a regular visitor.

The walled garden was created in the 1920s mixing Mediterranean influences with cottage garden planting and organic vegetable plots, ideas never previously mixed together.

One of the delights of the garden is when you come across a variety of sculptures, mosaic pavements and pools.

We had a guided tour of the house, which was very informative, but were unable to go up stairs, as they have no lift.

I was able to take some lovely photos in the garden; we had taken a picnic lunch & were able to find a relaxing spot to enjoy.

At the time of our visit there was an exhibition of textiles by Kaffe Fassett, he is an American born artist who is best known for his colourful designs in the decorative arts.

For those of you who may be interested please call 01323 811626.

Disabled admission price was £5.50 for the house & garden.

Frances Sandys



Living with half a brain, part one: we aren't lazy

by Abi, a brain injury survivor

How can you explain what it's like to wake up with your brain 'wiped'? Somebody who loses their sight might have trouble explaining how it feels, but at least they'd (probably) have their normal understanding and brain power and be able to use that to enable them to explain more easily. When I see or hear something I can't understand or there's a physical movement I can't do, I struggle to describe what exactly it is I'm not understanding or can't do, I think it's partly because one of the damaged bits of my brain includes the area used for talking and understanding of speech and maybe also because whatever bit is damaged that can't do the thing in question also can't communicate to my damaged speech centre; I can write better than I can talk. How can you describe what it's like to lose all your skills, including ones such as driving, cooking, reading, that you previously did on automatic? We could all do them before our ABI and most people still do all these things easily, we must, in order to live our lives. We aren't aware of any effort required to do them and carry out these tasks without thinking. Normally this invisible effort is something that goes on in the background, like when a PC is on 'background printing' you can ignore it and the computer can too, and get on with other stuff while that important job is being done. Our 'fatigue' (as it's called) is very different from any tiredness I had ever experienced before my ABI and is far worse than after a hard day at work, it is debilitating but so invisible.

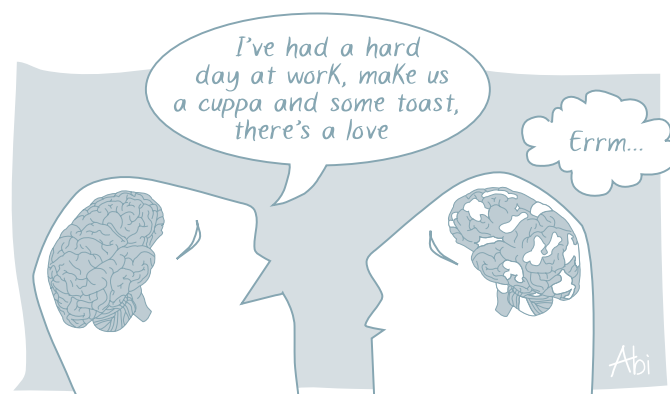
But when you have an acquired brain injury all these things need conscious thought and effort and actually some of the simplest things are really surprisingly complex. Take, for example, one of the things I've had most trouble with: cooking. But even the simplest version of that, such as making a cup of tea whilst at the same time grilling a piece of toast to go with it, was nigh impossible. Huh, you're thinking, how can THAT be hard? And I bet you think I'm exaggerating because it's so very far outside your experience (and mine too before), but I'm not. Let me try and explain: each movement of hand/body now takes a conscious thought: first get a mug, but then the lack of executive function gets in a muddle, would it be better to go to the kettle and switch it on to boil first? How long does it take to boil (your know-ledge of time has gone/is distorted)? So you dither weighing up which task to start first; but then you realise this is daft, you have to put water in the kettle first, silly me! So you pick up the kettle, forget it's empty and use the power/force it would take to lift a full kettle so your hand lifts it too fast and too high and it bashes on the overhead cupboards, chips the wood and a splinter flies off, you resist the urge to find the splinter, not easy but mustn't get distracted - at the start I didn't even know, nor could do, that. So, put water in, now it's heavier and harder to carry to its plug; you turn it on.

Then to put the grill on, I now know how to do that and not mix it up with the oven; luckily it has automatic electronic ignition otherwise I'd burn myself doing that as I did so often at the start when cooking - and the kitchen, pans and tea towels. Now everything is happening at once and it all becomes a muddle in my brain: get bread out/get mug/put teabag in/put bread under grill/deal with already boiling kettle. Leave kettle,

too much going on at once; open then close fridge, confused, turn round and realise what you went to get. While dithering, 'why did I open the fridge?', thinking through treacle... smell toast, heart thumping. Oddly my sense of smell became super-acute after my ABI, others lose it and can't use odours as a warning of something cooked or burning nor of needing to wash. Almost total lack of any feeling for time passing and because everything takes so much longer now means you've forgotten the toast and it's ready. Quick, get it out but then the phone rings and you forget the toast, dither about whether to answer but know you must only do one thing at a time now so ignore it, they'll ring again. Turn back to grill, lucky I can smell it, even so, at the start, I forgot I was cooking and left the room, now I know I can't do that because that caused fires.

Then I get the strange 'new' feeling, frequently now, of doing something well known but it feels like you've never done it before or been there before, 'jamais vu'. Get a knife, cack-handed because it's now hard to hold/organise holding different things at once in both hands; scrape black off and break the toast in the process, worrying whether to put the crumbs in the sink, in the washing up water or in the bin. Each decision takes quite a few seconds, everything takes far longer and is so difficult, so many little decisions and how on earth do you decide? All such hard work, brain getting tired now. Back to fridge, get out jam and marge, must put them on the cluttered table, not much room, brain must not only see but try to make sense of what it sees, organise if the space is big enough, and two things, easier if one; jumble in brain and vision, not able to unscramble the mass of shapes and colours of all the things on the table nor how big they are, nor understand the pattern of what and where things are, so confusing. But eventually you put jam and marge down. 'Oh, need a plate to put toast on and a knife', turn to get them, hand gets confused with kettle, pick up spoon by mistake; take top off jam or marge first, how to know which? And so it goes on... and every task is like this.


So then, after you've eaten and drunk what you made and are feeling so proud you did it, you have to lie down because you're so completely exhausted from the effort. Now can you see why we ABlers get so tired? Please will you now show a little understanding and stop complaining that we're always lying on the sofa and telling us that we're downright lazy.



Understanding ABI #72


Hawaiian Charity Family Fun Day

Saturday 28th July from 10 am



The Cabin are putting on a big family fun day !

- Open mic - local talented acts - Inflatable fun challenges
- Fancy dress - (prizes for adults and children)
- Face painting - Outside bar - All day BBQ - Sumo suits
- A unique IPA beer with all money going to Headway
- Candy floss and Ice cream - Childrens treasure hunt
- Cake and craft stalls - Raffle - Limbo !
- Colouring in competition



The Cabin
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A Note from the Editor

I hope that the new format for Headway Hurstwood Park's newsletter is what the readers want to see and read. If any of you would like to comment on the content or have any ideas that you feel would make the newsletter more interesting I would be very happy to hear from you. Also if you have an item of interest or would just like to include an article please do not hesitate in forwarding it to me (with the heading HHP newsletter), I will always try to find a place for it.

Best wishes,

Norma Speller

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