News and Views Ninth Edition.

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Hettie can be contacted at **telephone 028 3839 4088**, or email: Hettie.McKeown@southerntrust.hscni.net

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If so please contact your local Resource Centre.

Telephone numbers are included on page two/track two.

Contact details:

The Sensory Disability Teams are based at two locations.
For people who have had services from Moy Resource Centre, or if you live West of the Newry Canal and South Armagh please contact:

Sensory Disability Team; Jackson Hall; Main Building; St Luke's Hospital; Loughgall Road; Armagh; BT61 9 FQ.
Telephone 028 3741 2364. Mobile 07919 10350.
FAX 028 3741 2087. Minicom 028 3741 2421

If you received services from Conifers Resource Centre and live East of the Newry Canal and South Down please contact:

Sensory Disability Team; Cherrytrees Resource Centre; 1a Edenderry Gardens; Portadown; BT63 5EA.
Telephone 02838394088. Mobile 0783 929124.
FAX 02838394095. Minicom 02838394738
If you are not sure which office to contact, please do not hesitate to telephone any of the numbers provided and a member of staff will clarify the position for you and direct you to the appropriate member of staff.

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Monocular Vision – A Personal View

I had poor vision in my left eye for many years as the result of a car accident but learned to cope with difficulties, thankful for the good sight in my right eye. Several operations, including a corneal graft, failed, but I always reassured myself that, if anything happened to my good eye, I would not be blind, because new techniques would enable doctors to provide me with useful vision in my badly damaged eye.

Eight years ago, my left eye haemorrhaged and I was totally unprepared for the traumatic experience of having an eye removed. I added two new words to my vocabulary – enucleation and prosthesis! As I lay in my hospital bed, I longed for the surgery which would release me from the excruciating pain, trusting the Consultant, who explained that surgery was the only course of action available at this stage. I had perfectly good sight in one eye, so I was not blind or even partially- sighted. I worried about my appearance (I still do!) but I didn't really foresee any major problems. I should have known better!

The first problem was dealing with the violent sickness after surgery. I don't know whether this was just a bad reaction to the anaesthetic or whether it was directly linked to enucleation. (Removal of an eye!) Whichever it was, it made a lasting impression!

Next I had to deal with a wide range of emotions. I was happy to be pain free but experienced a huge sense of loss. I no longer had the back-up of a second eye, so was very anxious that, if anything happened to my good eye, I would be blind. Eight years later, that anxiety still remains and was greatly heightened recently, when I required cataract surgery!

I was extremely sensitive about my appearance. The empty socket needed time to heal so I could not be fitted for my prosthesis, (Another way of saying artificial eye!), for a number of weeks. The eye patch which was required during this time, attracted attention and my loss was accentuated by well-meaning people who enquired about my “sore eye”. If only they knew! I was so emotional that I couldn’t talk about my loss without dissolving into tears, so I tended to tell the truth, (“I have had an operation”) but not the whole truth, (enucleation never was mentioned!) I didn’t like being the centre of attention (I still do not!) and looked forward to the day when I could be fitted with my new eye and once more blend in with the crowd.

I was eventually fitted with my prosthesis and must pay tribute to Nick, at the RVH, who took so much time and patience to get as good a match as possible. Thanks to him I was able to resume normal life and gained enough confidence to face cameras (although I still do not like close-ups!) All I had to do was learn to live with Monocular Vision!

You would be forgiven for thinking that, if you have one eye with good vision, you will function just the same as a person with two eyes. This has not been my experience, although I hasten to add, in time you can function well enough to do everything you did before losing the sight of an eye – you just need to exercise caution!

Studies have shown that adults who lose the sight in one eye have declines in their ability to accurately track moving objects, to judge distance and to perceive depths. This perhaps explains why I am useless at ball games – I drop the ball more often than I catch it! I also have difficulty judging space when driving & always exercise extra caution when overtaking, even parked vehicles. This amuses my husband, who, if I stop, has been known to comment “I could take a double-decker bus through there!” I also have to be careful when coming down stairs. The last step, particularly on carpeted stairs, has a habit of disappearing, making me think that I am on the bottom step when I’m not!

I have difficulties with any task which requires bringing two hands together to match or join small objects. E.g. I cannot thread a needle without a needle threader. No-one in our house will hold a nail for me to hit with a hammer, as I am more likely to hit thumbs! I regularly try to use a brush & shovel with the shovel turned upside down and only realise my mistake when the dirt falls over the edge! I have read and it is my personal experience, that a person with monocular vision will have more collisions when walking, especially on the side where they have lost the vision. It is possible to learn to turn the head slightly & scan for obstacles with the good eye but if you are walking & talking with friends, extra care is required to prevent collisions with other pedestrians, overhanging bushes, parked vehicles or street furniture.

After misjudging the space I need to get through a door, I have learned to open doors wider than I think! I have also discovered that a kitchen cupboard door, if left open, is a lethal weapon!
In time, it is possible to learn how to consciously use one eye and the other senses to gather the information which two eyes can gather effortlessly. You may find the following practical tips helpful:-

- If going out for a meal, make sure your friend/partner sits on your seeing side. Watch out for waiters/other diners on your blind side.

- To avoid spillage when pouring liquids, rest the upper container on the rim of the lower one.

- When putting a cup/glass down, place your free hand on the table, then place your drink beside your hand.

- To reduce collisions with other people or objects, always take a good look around before making any sudden turns.

- Move cautiously on stairs, using handrail where possible.

- Open doors fully, or keep them tightly shut.

As I said earlier, with time and practice, a person with sight in one eye can function well enough to do everything he/she could do before loss of vision. However, it must be acknowledged, there is a permanent impairment of function in some activities. Example Drivers have trouble parking vehicles and reversing on the blind side & they also cannot see on the affected side when driving out of a junction, particularly if there are high banks or hedges. The best advice I can give would be “Proceed with Caution and Keep Motoring!”

Anonymous

Sleep Disorder

By Alyssa A. Botelho

When Jerry Berrier dreams, he hears and touches and smells and talks, but he doesn’t see. Blind since birth, he rarely remembers his dreams, however, because his sleep has been so poor.

At 15, Berrier had both of his eyes removed and lost the little light perception he had as a child. Now 60, he has battled a vicious sleep cycle — a few days of sleep followed by weeks of hardly any. The bouts of sleeplessness come suddenly and subside without warning. When they hit, Berrier can’t sleep more than a couple hours a night, no matter how tired he is.

Though physicians haven’t given him a formal diagnosis, scientists believe he suffers from a rare condition called non-24 sleep-wake disorder, or “non-24.” The chronic condition is characterized by a body clock that is out of synch with the 24-hour cycle of the Earth day.

Non-24 can affect those with normal vision, but it especially plagues the totally blind who can’t perceive light, the strongest external signal that keeps the brain’s sleep-wake cycle aligned to the pattern of night and day. Of approximately 100,000 totally blind people in the United States, anywhere from 55 percent to 70 percent of them may suffer from non-24.

The toll of having an internal clock in competition with the 24-hour world can be high, adding another layer of challenge to life without sight.

Internal clocks run slightly longer than 24 hours. In the sighted, the clock is reset daily. But the totally blind lack this master reset mechanism.

“There are some people who have said to me that having this sleep problem is worse than being blind,” Lockley said. “It’s a very difficult concept for sighted people to imagine — what could be worse than losing your vision?”

In 1989 Randy Pierce, one year out of college, he was struck by a mysterious neurological disorder. In two weeks, it had ravaged his eyes and reduced his sight to fuzzy tunnel vision. In 2000, he went totally blind.

That was also the year he stopped sleeping well. In the 13 years since, Pierce said he has averaged three to four hours of sleep a night.

“Blindness is a visible challenge but this sleep disorder is totally invisible. Nobody would have any idea why I felt sick or unfocused, and they would judge,” Pierce said. “I would feel dumb and I’m not a dumb man. I would feel lazy, and I’m not a lazy man. It’s a very powerful invisible malady.”

The cause of Pierce’s sleep troubles, like Berrier’s, can be traced to a malfunctioning body clock. Most people’s internal clocks naturally run slightly longer than 24 hours. Among the sighted, the clock is reset each day by signals from light-sensing cells in the eyes. But those who are totally blind lack this master reset mechanism.

In theory, a blind person with a cycle of 24.5 hours would feel ready for sleep 30 minutes later each day. In about three weeks — as the body’s natural bedtime inches its way around the clock — the brain’s “biological night” would be in the middle of the afternoon. This is when weeks of bad sleep suddenly strike for blind people struggling to maintain a normal schedule. Their fatigue is similar to that of someone traveling across time zones.

For Pierce, non-24 compromises the alertness and memory he said are critical for a blind person.

Remembering how the clothes are stacked in his closet, or where the keys are, or the path to an unfamiliar place become difficult during sleepless periods. He records reminders into his phone constantly so he won’t miss appointments.

“As a blind guy, I have to be concentrating all the time,” he said. “I have to remember where the door is and where the counters are just so I can get around.”

For both Berrier and Pierce, maintaining social and professional lives can be a challenge. Berrier, a technology consultant, has kept a job for most of his life but often skips evening activities with friends. In sleepless weeks, Pierce is forced to schedule a day of recuperation for every day of work running his nonprofit business or when he has to speak at schools.

Over the years, both men have been diagnosed with everything from depression to narcolepsy to insomnia. They both have tried a host of sleeping pills, to no avail.

There are no medications approved by the US Food and Drug Administration to treat non-24. Some people have found relief from synthetic supplements of the hormone melatonin, which sends a “nighttime” signal to the body clock. But the treatment doesn’t work for everyone.

The ongoing clinical trial is testing a candidate drug called tasimelteon that scientists hope will be more effective in treating non-24.

The development of an effective treatment could mean more than a good night’s sleep for those with non-24. The disorder may interfere with the body’s regulation of metabolism, mood, and cognition.

Berrier’s wife, Elaine, said non-24 has been a part of their entire 39 years of married life. Elaine, 60, is sighted, but as a retired nurse, she knows the toll of working an overnight shift, which has similar effects on a person’s body. She worries about how decades of similar fatigue have affected her husband.

“He often only gets three hours of sleep a night — I know that can shorten a life,” she said.

For Pierce, sleep loss has caused longer healing times. In the mid-2000s, he endured several neurological treatments to help the region of his brain that controls balance. He said that during his recuperation wounds took longer than normal to mend.

Both men are now taking tasimelteon daily, and have noticed improvement. They said they plan to use the drug if it hits the market, though Pierce wonders how he would afford the drug if it’s expensive.

The drug hasn’t worked perfectly for Berrier, but he now is more likely to have one night of bad sleep rather than weeks.

Last year, while on the treatment, Pierce became the first blind person (and his pup, The Mighty Quinn, the first guide dog) to climb all 48 of the 4,000-foot peaks in New Hampshire’s White Mountains in a single winter.

He said he would have attempted the winter climbs regardless, but the extra sleep made the ascents that much swifter.

Editor’s note: unfortunately neither melatonin nor tasimelteon treatments are currently available within the United Kingdom.

Sound Connections 2 Project by Ruth Gillespie

Following the great success of Sound Connections in 2012 a second Project, funded by the Ulster Museum and arranged by Sally Walmsley is currently taking place on Friday mornings in St. Patrick's Primary School in Armagh.

Last year there were 10 Primary 7 children from Saints and Scholars Primary School, also in Armagh, and this year there are 31 Primary 5 children and 10 visually impaired adults. A visit to the museum at the start of the project was very interesting and the exhibits were described for the benefit of the VIP's. The task now is to make sound scapes to accompany the exhibits and this is being done at the school. As well as Sally's wonderful musical arrangements when all children and adults play various instruments from drums to all kinds of harps, brass and George from the museum on his guitar and Sally on piano makes it extremely good fun.

George adds a bit of history by bringing an object from the museum each week which is discussed within the group. The children are very enthusiastic about the project, as are the adults and much fun is had by all. Mrs Bennett, the Primary 5 teacher is greatly interested and her class are very well behaved and a great help to the adults with their guiding skills taught to them by Denise Lavery, Rehabilitation Worker with the Southern Health and Social Care Trust. On the final day, 22nd March, the music which has been created will be presented by all involved at the museum in Belfast. The project is another big success and hopefully funding will be available to repeat it in 2014.

BEN NEVIS CHALLENGE 2012

In the last edition of the News and Views we featured an article that described how a group of Blind and Partially Sighted People had spent a weekend at the Tullymore Centre and had climbed Slieve Donard as part of their training to climb Ben Nevis. Some of the participants described what happened and why they took part, this is their story.

We love bagging Munroe’s and this time all fifteen of us bagged the biggest one of them all.

Why did we do it?….because we had to….prove to ourselves that we could do it…..do what?…..climb the UK's highest mountain…..why us?… not because we are British or German or Irish or Scottish…but because we couldn't see where we were going…. ok its usually misty and foggy up there at 4500 feet….big deal…it’s the same challenge for everyone…of course it is… that's why we did it…..but the difference is we spend every day of our lives walking and climbing through the mist and fog…..We are normal people doing normal things….and We are BLIND.

Breaking records the first time that a large group of blind and partially sighted people have attempted and successfully completed the Ben Nevis Challenge. Seven totally blind and eight partially sighted people along with their guides and supported by the RNIB Northern Ireland Sensory Engagement programme did so on the 10 September 2012.

The morning arrived all wet and misty. The sun was trying to fight through the clouds but it was taking some time. The climb began. Through sun, wind, rain, hail (like shards of glass) and sleet …We marched, walked, stumbled and pulled ourselves higher into the clouds. It was hard…..harder than some of us imagined.

Madeline hit a wall (just like when running a marathon) …..her back burned with such pain that she couldn’t move….How the heck was she going to get to the top?

She was just about to tell one of the leaders/guides that she could not go on when she remembered Danny McSherry's early morning chant, 'One for all and All for one. Never, never give up'. Now how can you turn back when you’ve got that in your mind? I was a sorry Rathfriland girl who wasn’t fit as I wanted to be, having fallen down the stairs and off the bed a few weeks previous and had to turn back having only got half way up Slieve Donard on a training climb. But this was not going to be my last attempt…….onward and upward.

I continued for another 40 minutes when the second surges of pain cut through ……..I needed something to get me to the top. An energy drink and nutrient bar didn’t do it. I stopped for a moment and this lady, one of the group from Dundalk stopped beside me…..Both of us hanging (you know how you hold yourself when you just cannot go on?)……sorry looking athletes.

“I can’t do this” she said. “Me neither dude…but I am not a quitter” Martin, my guide supporting me, "Madeline check your bloods," he said. Well in an instant I said, after a jab of insulin “come on….if 10 people can get a wheelchair bound volunteer up this brutal hill ….then we can do this” and Babs and I both just looked at each other and nearly ran to the top.

That moment I was grateful for….as within 20 feet of my “feeling sorry for myself” ….was indeed the summit of Ben Nevis waiting for us. Oh how we danced for joy. So much so with a wee drop of Bailey's in our belly we skipped, hopped, jumped, leaped, ran all the way back down in no time. Our legs shook with energy and our hearts shook with joy.
Job done.

'Bagging' Munroe (a Munroe is a mountain in Scotland over 3000 feet)

Article submitted by:
Danny McSherry; RNIB NI Project Coordinator; Sensory Engagement Project (SEP).
SEP - A partnership project between RNIB, Action on Hearing Loss (formerly RNID), NCBI and DeafHear funded by the EU's INTERRREG IVA Programme, managed by the SEUPB.

Hope City Project – Article by Ruth Gillespie

The Hope City is a project funded by the Southern Health and Social Care Trust Arts Care and managed by Artist in Residence, Eddie Rafferty.

The project, which has been running for about a year includes service users with various disabilities and ethnic backgrounds. Currently three visually impaired people attend Eddie's studio at St. Luke's Hospital in Armagh each Monday and the theme for their project is "The Wheel of Life".

The wheel, constructed by Eddie is modelled on the London Eye and each individual is making objects from old newspapers, dating back as far as the 1920's, which are then mounted on board and these will be hung on the wheel. These objects, which are chosen by the VIP's, depict their own interests and the old newspaper is a form of "recycling".

The finished wheels along with many other models from other people with physical, mental health and sensory disabilities will be shown at the Market Place Theatre in Armagh in September 2013.

This will be an amazing exhibition and well worth visiting and it's all thanks to the wonderful artistic talent of Eddie who is really passionate about the project and makes it's so enjoyable for the participants.

A trip to Sicily including a hike up Mount Etna.
By Margaret Davidson.

Last September my husband had a big birthday, yes one of those that ends in a naught!

In order to celebrate this birthday he decided that he would like to go on a trip to Sicily. For those of you who don't know Sicily is an island at the toe of Italy, Italy is shaped like a boot and Sicily is shaped like a ball at the toe of the boot. We left home at 4.00 a.m. on a Sunday morning when it was still dark and drove to Dublin Airport. When we arrived at Dublin Airport I could not believe the chaos that met us there. I was astounded that there were so many people about at 05.30 a.m. on a Sunday morning. Eventually we reached the check in desk and when my husband booked the holiday he had stated that his wife was registered blind and that we may need some assistance. The check in clerk showed my husband a shorter way to the departure gate, which meant we did not have to go through the building and go up and down steps and escalators.

At 7.00 a.m. we boarded the Air Lingus Plane and left the cool autumn breeze in Dublin. After flying for four hours we arrived in Sicily were it was 24 degrees centigrade. My husband and I remained on the plane until all other passengers had got off which made it easier for us to get off. This also meant we did not have to wait long at the carousel to collect our luggage. Next we found our English speaking Top flight Courier who escorted us to the Coach which took us to our Hotel. The hotel was called The Savi Doro which in English means the Golden Beach. There was a beautiful golden private beach across the road from the Hotel. As it was private we were assured of our sunbeds and parasols and we could order our lunch from the hotel and it was brought to us on the beach.

We booked into the Hotel on a bed and breakfast basis and went out to different restaurants each night. On the second night we found a lovely restaurant which we kept returning to. As I was not at home, I had taken my white stick with me and because I had my white stick with me the staff were very helpful. The head waiter came over to me and stated if that I wanted any fish filleted, or wanted my food cut up it would not be a problem. Indeed I took advantage of their helpfulness and found that they were very obliging.

Included in the cost of the holiday were various trips and we went on all of them, but the one that I would like to tell you about is the trip up to Mount Etna. Mount Etna is Europe’s largest active volcano. Following breakfast one morning a coach picked us up and took us to the lowest slopes of Mount Etna, to a height of nineteen hundred metres. Here we put on jumpers and coats and good walking shoes as advised by our Courier. Although it was very warm at ground level the higher up the mountain you go the colder it gets. Next we went up various flights of steps and got into a cable car which held six people which took us further up the mountain.

When we got out of the cable car I had my husband’s arm with one hand and my white stick in the other hand. We climbed onwards and upwards, over the black ash like lava. We then got into what was called a jeep, but it was really a four wheel drive bus. We climbed into the bus and it drove us a little further up the mountain. Once we got out of the bus we buttoned up our coats, and put our hats and gloves on, because there was an extremely cold wind. We plodded onwards and upwards towards the secondary crater. We could feel a really cold wind on one side of our body and heat from the secondary crater on the other side of our body.

The Main Crater last erupted in 2002 and it was still smoking when we were there. Apparently when it erupted in 2002 it destroyed a house that was on the side of the mountain. We went to the secondary crater and there was still steam coming out of it, and for those who could see the lava inside the crater they described it as black ash or cinders. The guide at the crater informed us that there are many different minerals in the molten lava. This results in the ground where it lands becoming very fertile in future years.

Following this very informative talk we returned down the mountain by bus, cable car, and coach removing layers of clothes as we did so, because the further we descended the mountain the higher the temperature got. I found this trip very interesting. For those who have lost their sight and do not have a guide dog, I would advise them to take their long white cane with them, as I found it to be very helpful on all occasions.

Article on the New ‘Tap Tap See’ App by Ruth Gillespie

Tap Tap See is a mobile app especially designed for visually impaired people who use IOS devices – iPhone, iPad and iPod.

It’s essentially a camera and when the app is opened voiceover will say “double tap to take a picture of what’s in front of you”. Voiceover will describe the object very accurately.
It can even identify e.g. Heinz Baked Beans as opposed to Tesco own Brand Baked Beans. The app is very easy to download and the nicest thing is it’s free from the app store.

Other feedback received on this app has been very positive as follows:

“… you just take a pic and the app does a very good job of identifying the object. You don't need to do anything else.

I think this app is one of the best I have ever downloaded. Here are a few of the things I've tested it on with great success, trying it out for a class of students thinking of buying iPhones.

Identified a ten pound note, identified shampoo and conditioner bottles, told me colour of shirts, told me pattern on duvet, identified jar of coffee, identified can of coke, read title of CD, and more… I have been chatting to others on Twitter and the overall verdict is that this app is great.

I don't know how it works, just that it does, and brilliantly.”
Ruth finishes by saying that this is a “Highly recommended app.”

Boccia, Article by Anne Willis

Boccia is a game similar to bowls and is played with soft leather balls. It was initially invented for people with cerebral palsy, but has now become a favourite for many people with varied disabilities. By 2008 more than 50 countries were playing the game.

Although it became a paralympic sport in 1984 I had never heard of it. When fit 4 u started 6 years ago it was introduced as one of the activities and has grown in popularity ever since. Here at the Dungannon club we have our boccia on the first Monday of every month.

Two teams made up of two or three people play, each team has six balls of either red or blue. We play our games from a seated position. The game is usually placed over four ends. The first person throws a white ball called the jack; this must cross a designated line to be a valid throw. They then throw their coloured ball aiming to get as close as possible to the jack, then the first person from the opposing team throws a ball either trying to get it closer to the jack or knock their opponents ball out of the way. The team whose ball is furthest from the jack on each throw continues to play until all balls have been played. After each end all balls of the same colour nearest the jack are worth one point. We really enjoy the game and can get quite competitive. Each member of the winning team gets a little silver cup to take home for a month, then it's back the next month to do it all again. We have been to boccia tournaments in Antrim, Newry, Armagh and Cookstown. Sadly we have not been winners at any of these events, but we have enjoyed the day out and hope for better results next time.

Belfast donkey riding therapy Saturday club

PRESS RELEASE from The Donkey Sanctuary

20th February 2013

Children with additional needs can benefit from therapeutic donkey rides at The Donkey Sanctuary's donkey assisted therapy centre in Belfast through its unique 'Saturday Club' event.

The club, held on the second Saturday of every month, enables children with additional needs to ride the donkeys with their brothers and sisters. Riding therapy can help improve a child's self-esteem and confidence, and physically aids the development of fine motor skills, core stability and hand eye coordination. The donkeys also enjoy the tactile interaction they have with the children who visit.

Tina Symington, who runs the Belfast donkey assisted therapy centre, says: "For families with children with additional needs it can be a challenge to find activities that all your children can enjoy together. The beauty of riding therapy with our donkeys is that the children are all able to participate and share a fun morning with their siblings, and they can achieve so much riding a donkey. Parents and carers can relax over a cup of tea or coffee and have the opportunity to meet other parents, carers and supporters."

"We also provide drop-in sessions which run on selected Tuesdays and Thursdays during school holidays. Booking is required in advance for each event so please get in touch to avoid disappointment."

For further information or to book a Saturday Club session please contact the centre on 01395 573009 or visit www.thedonkeysanctuary.org.uk/riding-therapy.

Boccia a game for everyone.

Lurgan Mail reporter Graeme Cousins went along to Craigavon Leisure Centre this week to see first-hand what’s involved in a game of Boccia, the paralympic sport which is proving a big hit in the borough.

“Every Monday afternoon Boccia enthusiasts gather at Craigavon Leisure Centre for an activity which is as much about socialising as it is about sport.

Most, but not all, of those taking part, have some level of disability. Some of the members are accompanied by able-bodied friends, family and carer, but the beauty of the sport is it creates a level playing field for everyone taking part.

I had the pleasure of joining the group for a session on Monday. It was a welcome opportunity to get involved in some physical activity, having been frustrated when both the rugby and football matches I was due to play in were cancelled at the weekend due to snow.

Boccia (pronounced Bot-cha), is a paralympic sport introduced in 1984. It mightn’t be as strenuous as rugby or football, but it’s no less competitive.

It’s played in teams of three and everyone taking part is seated. Boccia is played in a format similar to bowls in that a jack is bowled to pitch the game then teams take it in turn to get closest to the jack. The balls used are soft and can be thrown, kicked or propelled down a ramp.

I found myself in a team with Alex McVeigh and his wife Susan who has Multiple Sclerosis. It was fair to say I was the weak link. I skipped the warm up target practice exercise and it was to my cost. It took me a while to get used to the weight of the balls during which time we’d already lost both our matches.

Thankfully it’s the taking part that counts in Boccia and it’s clear to see that everyone involved thoroughly enjoyed themselves. Young Susie Whitten is a prime example of why activities like Boccia are vital to disabled people in Craigavon. Susie is blind and has physical disabilities. She attends the sessions with her dad Trevor and her friend and carer Debbie Millar.

In order to aim at the target she is given directions by Debbie and her dad and she’s also given an indication of where to aim by the sound of the coach clapping close to the jack.

“Susie is amazing,” said Boccia enthusiast and wheelchair user Eric Flowers. “She’s an absolute joy to watch. She doesn’t let anything hold her back.”

For deaf couple Alan Hollywood and Louise Thompson the Boccia sessions are the highlight of their week. Despite the snow on Monday they weren’t to be deterred from attending.

The Boccia session are taken by Colleen Murray, the Inclusive Sports and Leisure Officer from Disability Sport Northern Ireland and David Mayers, Craigavon Borough Council’s Active Communities Disability and Multi Skills Coach.

Colleen, who is 27 and from Derrytrasna, told me: “The most important aspect of the Boccia sessions is inclusivity. Although it’s designed for people with Cerebral Palsy and high levels of physical disabilities anyone with any level of disability, including learning disabilities, can play. Carers, family and friends are also welcome to join in and it makes for a great mix.

“We get up to 20 at the sessions on Monday, then at the end of the month there’s a big competition where we’ll have 50 plus in attendance from different disability organisations and individuals from across the borough.”

“It started out as a monthly session, but now it’s once a week, which tells you how quickly it’s grown.”

As well as the Boccia sessions from 1.45pm to 2.45pm on Mondays, Craigavon Leisure Centre also hosts New Age Kurling for people with disabilities on Thursdays from 1.30pm to 2.30pm.

For more information on Boccia and other disability activities in Craigavon email colleenmurray@dsni.co.uk or phone 3834 1333 or 0776 925 0885.

Article for Visual Disability News, Northern Ireland

When friendship really matters

As a reader of ***Visual Disability News***, you may be comfortable with your sight loss because you've had time to get used to it. But can you recall when you first had that diagnosis? Were you fearful? Confused? Shocked? Did you feel isolated?

John said, 'I decided I was never going to go out again. I was going to stay in the house… it was too terrifying.'

Christine felt overwhelmed. 'Sight loss affects everything you do, because the world is so visual… not being able to see faces when watching TV, not being able to see what's on the shelves at the supermarket… '

Blindness is the disability that the majority of people say they would most fear. But every day in Northern Ireland, 10 people learn that they are unavoidably losing their sight, possibly becoming blind. Over 50,000 people are affected by sight loss across Northern Ireland. As our population ages, these numbers will increase. Almost one in four of us will know what it is to live with a disabling level of sight loss. The main causes of sight loss are age-related macular degeneration, cataracts, glaucoma and diabetes.

Emotionally, sight loss can bring a sense of isolation and exclusion. And, practically speaking, the list of difficulties is endless. Loss of mobility makes it challenging to leave the house. Everyday activities such as cleaning, shopping and cooking become harder. Some describe the trauma of sight loss as akin to a close family bereavement.

Despite this level of impact, only one in five people has someone with them who can support them either at diagnosis or afterwards. People often find themselves with no way of making friendships and no support in adapting their normal activities. Acute loneliness and clinical depression are not uncommon.

Torch Trust, a long-established Christian organisation working with people with sight loss, is changing what it offers to better tackle current issues. Alongside its large free lending library of Christian materials and free magazines, new initiatives are under way to provide for important social needs. **Torch Fellowship**

Groups, of which there are more than 100 – eight of them in Northern Ireland – have been meeting for many years. Usually this is a monthly gathering of 20 to 40 blind and partially sighted people and sighted helpers, run at a convenient location by local volunteers. But now new models of smaller groups are being well received. The newcomers are **TorchTalk Groups** and **Torch Book Groups**.

TorchTalk Groups are essentially telephone friendship groups. Six to nine people are linked weekly by a conference call. The conversation is guided by a trained facilitator, with a focus on Christian fellowship and encouragement, as well as talking over personal needs when appropriate. This is ideal for people with no fellowship group within reach and can prove to be a real lifeline.

Torch Book Groups are small, intimate groups, often meeting in homes, where discussion is based around audio books. Torch Trust facilitates this by supplying materials of the group's choice, and even makes starter questions available to get the conversation under way.

Torch also runs **Moving Forward** breaks – short residential breaks at its Holiday & Retreat Centre in Sussex, not too far from Gatwick Airport – where people newly-diagnosed with sight loss are given practical and emotional support towards making a positive adjustment. The combination of professional advice and Christian care given to guests on a **Moving Forward** break can make a dramatic difference to their coping skills and confidence.

And now there is another new initiative, with the launch in Northern Ireland of a church-based befriending scheme bringing Christian volunteers alongside those adjusting to the unwelcome news of sight loss.

'Even where people have access to professional services through eye clinics and so on, the time offered is very limited. What they can give is measured in minutes – but in the befriending service we call **Journeying With**, we see time being given in hours and given regularly,' said Dr Gordon Temple, CEO of Torch Trust.

Dr Temple explains how the emphasis of what Torch offers is changing.

‘We want to “journey with” people with sight loss – to come alongside not as professionals but as friends. As true companions we will seek to support people who are losing their sight to find their way through their difficulties to access solutions. Whatever they are facing, they won’t do it alone.’

Northern Ireland was chosen to pilot the new **Journeying With** befriending scheme, starting in the Southern Trust area encompassing Lurgan, Craigavon, Portadown, Armagh, Dungannon, Dromore, Banbridge and Newry. Torch is recruiting and training prospective befrienders from local churches to respond to those struggling with their sight loss experience.

‘What people in the early stages of sight loss often need most is time – the time of someone who will encourage and support them as they come to terms with loss and rebuild their lives around their new circumstances. Studies show that a little well-judged help in the early stages not only helps the person losing their sight to cope better, but also leads to greater long-term independence,’ says Dr Temple.

The **Journeying With** service has been welcomed by professionals working in the field, and will be offered to people of any faith or none, in common with all that Torch does. Torch is looking to recruit mature Christians who have a few hours a week to spend with a blind person over a period of up to 26 weeks.

Torch Trust work in Northern Ireland is directed by Leonard Campbell. Recently Leonard attended a four day ECLO (Eye Clinic Liaison Officer) training course run by RNIB.

‘This has given me a much deeper understanding of eye conditions and the different issues faced by people losing their sight,’ he said. ‘I have become more aware of the importance of providing the right support at the appropriate time and the positive impact it can have.’

To find out more about Torch Trust, the **Journeying With** project or Torch groups in Northern Ireland, contact Leonard Campbell on 0289 266 1932 or email leonardc@torchtrust.org .

www.torchtrust.org/JourneyingWith

www.torchtrust.org

Five ways to wellbeing

Take small, simple steps to make your workplace mentally healthier.

These five steps have been researched and developed by the New Economics Foundation. Let us know if you're going to or have done any of these ideas on Facebook.

Connect

There is strong evidence that indicates that feeling close to, and valued by, other people is a fundamental human need and one that contributes to functioning well in the world.

It’s clear that social relationships are critical for promoting wellbeing and for acting as a buffer against mental ill health for people of all ages.

With this in mind, try to do something different today and make a connection.

- Talk to someone instead of sending an email.
- Speak to someone new.
- Ask how someone’s weekend was and really listen when they tell you.
- Put five minutes aside to find out how someone really is.
- Give a colleague a lift to work or share the journey home with them.

Be active

Regular physical activity is associated with lower rates of depression and anxiety across all age groups.

Exercise is essential for slowing age-related cognitive decline and for promoting well-being.

But it doesn’t need to be particularly intense for you to feel good - slower-paced activities, such as walking, can have the benefit of encouraging social interactions as well providing some level of exercise.

Today, why not get physical? Here are a few ideas:

- Take the stairs not the lift.
- Go for a walk at lunchtime.
- Walk into work - perhaps with a colleague – so you can ‘connect’ as well.
- Get off the bus one stop earlier than usual and walk the final part of your journey to work.
- Organise a work sporting activity.
- Have a kick-about in a local park.
- Do some ‘easy exercise’, like stretching, before you leave for work in the morning.
- Walk to someone’s desk instead of calling or emailing.

Take notice

Reminding yourself to ‘take notice’ can strengthen and broaden awareness.

Studies have shown that being aware of what is taking place in the present directly enhances your well-being and savouring ‘the moment’ can help to reaffirm your life priorities.

Heightened awareness also enhances your self-understanding and allows you to make positive choices based on your own values and motivations.

Take some time to enjoy the moment and the environment around you. Here are a few ideas:

- Get a plant for your workspace.
- Have a ‘clear the clutter’ day.
- Take notice of how your colleagues are feeling or acting.
- Take a different route on your journey to or from work.
- Visit a new place for lunch.

Learn

Continued learning through life enhances self-esteem and encourages social interaction and a more active life.

Anecdotal evidence suggests that the opportunity to engage in work or educational activities particularly helps to lift older people out of depression.

The practice of setting goals, which is related to adult learning in particular, has been strongly associated with higher levels of wellbeing.

Why not learn something new today? Here are a few more ideas:

- Find out something about your colleagues.
- Sign up for a class.
- Read the news or a book.
- Set up a book club.
- Do a crossword or Sudoku.
- Research something you’ve always wondered about.
- Learn a new word

Give

Participation in social and community life has attracted a lot of attention in the field of wellbeing research.

Individuals who report a greater interest in helping others are more likely to rate themselves as happy.

Research into actions for promoting happiness has shown that committing an act of kindness once a week over a six-week period is associated with an increase in wellbeing.

PERSONAL INDEPENDENCE PAYMENT (PIP) UPDATE:

The following information has been taken from an information leaflet that the Disability Living Allowance/ new Personal Independence Payment department has produced. We trust that you find this information helpful.

KEY MESSAGES

- You do not need to do anything now.
- The dates given in this document may change, as they are subject to the Northern Ireland Welfare Reform Bill completing its passage through the Northern Ireland Assembly.
- Your Disability Living Allowance (DLA) will continue until you hear from us.
- We will contact you in plenty of time to tell you how and when to make a claim for PIP.
- The new benefit will impact people aged 16 – 64 years old.
- Unless you have a fixed term award of DLA or report a change in your condition after 7th October 2013, the earliest we will contact you is October 2015.

1. Why have I received information about PIP when I'm not affected?

Answer:

Everyone currently receiving DLA in Northern Ireland has received a letter about the introduction of PIP. It is important that we explain the change to all DLA customers at the same time. This will ensure that customers can understand clearly if they will or will not be impacted.

2. How and when will this affect me?

Answer:

If you are <u>under 16</u> and in receipt of DLA you will continue to receive it until you reach 16, when you will become eligible to apply for PIP.

If you **are <u>16 before 7 October 2013</u>** you will continue to be able to claim DLA. But in the same way as other people receiving the benefit, you will be asked to claim PIP at some point over the next few years.

If you are **16 on or after 7 October 2013** you will need to decide if you want to claim PIP. You do not need to do anything now. We will write to you or your parent / guardian in plenty of time to explain how to apply for the new benefit.

If you are 65 or over on 8 April 2013 you don't need to claim PIP. You can continue to claim DLA as long as you're still entitled to it.

If you have an existing DLA award which is due to end, or be reviewed, on or after 7 October 2013, (and you have not already received a renewal letter about your DLA), you will be asked to make a claim for PIP. We will write to you in plenty of time if you need to take any action. You do not need to do anything now**.**

If you report a change to your health condition on or after 7 October, you will be asked to make a claim for PIP. When you report the change we will explain what will happen next.

If you have an indefinite or lifetime award – and you do not report a change to your condition on or after 7 October – you will not be contacted until October 2015 or later. We'll write to you in plenty of time to explain. You do not need to do anything now**.**

3. What is Personal Independence Payment?

Answer:

DLA will be replaced this year by PIP for people aged from 16 – 64.

If you are aged under 16 or over 65 now, you will not be affected by the introduction of PIP.

People already claiming DLA will not be affected until October 2013 at the earliest.

If the change applies to you, we will let you know when and how to make a claim. You do not need to take any action now and your DLA will continue until you hear from us.

Please read the information letter we sent to you carefully.

4. When will I hear about this?

Answer:

You do not need to do anything about this now. We will contact you in plenty of time.

5. What will happen to my DLA?

Answer:

If, after we contact you about claiming PIP, you decide to apply, your DLA will continue to be paid until we make a decision about your PIP claim.

If you decide not to apply for PIP, your DLA will end.

6. Will this affect the car I receive under DLA?

Answer:

Your mobility needs will be assessed during your application process for PIP.

This may help you qualify for the Motability scheme.

7. I’m a carer and get Carer’s Allowance, what does this mean for me?

Answer:

If you receive Carer’s Allowance because the person you are caring for is entitled to DLA, then becoming entitled to the Daily Living component of PIP will similarly help you qualify for Carer’s Allowance.

8. Will this affect any other benefits I am getting?

Answer:

The support you are entitled to under DLA will remain broadly the same under PIP.

9. Where can I find further information?

Answer:

You can find out more information about PIP on our website www.nidirect.gov.uk/welfarereform

Alternatively, you can:

- Contact a local advisory service who can provide important help and support; or
- Call in at your local Jobs & Benefits Office / Social Security Office or the Benefit Shop in Castle Court, Belfast.

The Double A’s Cookery Corner.

Leek And Potato Soup   Serves 5-6

Ingredients:
2ozs butter
2 table spoons olive oil
2 large onions -chopped
12ozs potatoes -peeled &diced
5 leeks-chopped
1 clove garlic -crushed
4ozs streaky bacon -finely chopped
3 pts. chicken stock
Fresh parsley to garnish

Method:
Melt butter and olive oil in a large saucepan and gently fry bacon for a few minutes until cooked.
Add onions, garlic, leeks and potatoes.
Allow vegetables to cook for about 15 minutes. Stirring gently.
Add the stock and simmer for 30 minutes until the potatoes are cooked.
Season to taste.
Liquidize in a food processor then return to a clean saucepan and heat through.
When serving sprinkle top with a little chopped parsley.

Now following that lovely meal a few of you may feel like something sweet, so we hope that you enjoy the following desert:

BREAD AND BUTTER PUDDING - Serves four.

Ingredients:
4 thin slices bread, buttered
2ozs sultanas
1oz caster sugar
2 eggs
3/4pt milk
ground nutmeg

Method:
Cut bread into triangles and layer in a buttered ovenproof dish, sprinkling the sugar and sultanas between the layers.
Heat milk, do NOT boil.
Whisk eggs lightly and pour milk onto eggs stirring all the time.
Strain mixture over bread.
Sprinkle top with nutmeg and leave to stand for 15 minutes.
Bake at 180 degrees for 30-40minutes until set and lightly browned.
Serve with custard or fresh cream.

A Final Note from the Editorial Team.

The Editorial Team endeavours to include as many articles as possible from people with sight loss and we hope that you have enjoyed these and possibly learnt something from them.

If you have any interesting articles or would like to suggest an article for the newsletter, please let us know. We are especially looking for people to join our News and Views Editorial Team so if you would like to submit an article or join the team please contact your local Resource Centre as we would love to hear from you.

Yours sincerely,

Anne Willis - Editorial Committee Member
Ann Mallon - Editorial Committee Member
Laura O’Reilly - Editorial Committee Member
Gerald McEvoy - Editorial Committee Member
Katrina Boyd - Editorial Committee Member
Ruth Gillespie - Editorial Committee Member
Bronagh Lynch - Editorial Committee Member
Denise Lavery - Editorial Committee Member/Reader
Donal Connolly - Newsletter Reader
Ray Maxwell - Editor.

The Editorial Team would like to end this edition of the magazine with a:

THOUGHT FOR THE DAY:

> “The best and most beautiful things in the world cannot be seen or even touched – they must be felt with the heart.” Helen Keller