

## Expanding horizons – Opening doors

Spring/Summer 2018

Dear Unlimited Oxfordshire member,

Scientists and doctors still know little about the human brain even though they are making great strides in learning more about it - and what an amazing organ it is. For those people with damaged or diseased nerve cells it is reassuring to know that something as pleasurable as listening and moving to music could help regenerate the brain as shown in the following piece about music therapy.



It does seem the Government has struggled to make the best use of new technology so any improvements in this area are welcome - as Larry Gardiner found when he finally got the DWP to correspond by email.

There have been recent changes in EU law regarding data protection, called the General Data Protection Regulation. We are able to continue sending you information under something called 'legitimate interest' whereby Unlimited considers you to have an interest generally in disability matters. However it would be preferable if you could renew your membership form as the new law requires organisations to ask for renewed 'opt in' by people featuring on their databases.

Don O'Neal and John Wells visited Wolvercote Community Orchard to conduct an access survey and I recently visited the Naidex exhibition for the first time. It is odd that I had never heard of it until recently even though it has been running for many years. My review is included in this newsletter.

Unlimited Committee members have started the access survey of shops in Oxford. We would still welcome volunteers to take part. If you can help for a few hours please contact Unlimited.

Diane Sider, Editor



### Beat That Rhythm for Your Brain

Scientists have discovered that certain rhythms allow the brain to by-pass sections that have been damaged by stroke, traumatic injury or degenerative diseases such as Parkinson's and dementia. Rhythmic beats or songs with a strong connection to the patient have been shown to reactivate nerve cells and reboot the brain's sensory pathways to enable patients to communicate or recover physical ability.

'There is strong neurological evidence that music activates many different areas across the brain. The motor system is very sensitive to picking up cues from the auditory system so when we hear music, particularly pulse or rhythm, it kicks straight into the motor system going around the brain,' according to eminent music therapy professor Dr Wendy Magee, from Temple University Philadelphia. 'Music can engage alternative pathways for a specific function, such as language, depending on the size of the lesion or even effect changes in brain structures. Studies have shown that music might excite activity around small lesions to activate function and, with larger lesions, it seems the healthy side of the brain might take on roles and mechanisms the damaged side was previously responsible for.'

Dr Tamlin of the University of Melbourne, added: 'Rhythmic music has an amazing effect on movement coordination. Music can bypass damaged areas in the brain, providing a scaffold to do the part of the work the brain is not doing in coordinating movement.'

A patient with Parkinson's disease tried neurologic music therapy moving to his favourite tracks by Dire Straits. Within a few sessions he began to notice improvements in his balance and gait and, importantly for him, his confidence.

Naidex is Europe's most established trade, professional and public event dedicated to the care, rehabilitation and lifestyle of people with a disability or impairment. Held at the National Exhibition Centre in Birmingham over two days in April, this event returned for its 44th year showcasing 300 exhibitors, live demos, advice, Continuing Professional Development accredited seminars and providing networking opportunities. Naidex is completely free to attend and welcomes groups, families, colleagues and friends.

This was my first visit. Online registration was very easy and tickets arrived efficiently a couple of days later with an email confirming travel directions. It wasn't essential to register in advance, however, as this could also be done on arrival. I drove up from Oxford with my husband and the NEC is just off the motorway so there is no need to drive into Birmingham itself. We didn't arrive until 11.30 by which time all the designated disabled parking had been taken, so people were parking anywhere they could but there were few restrictions. Parking was free to Blue Badge holders but we were quite a distance from the relevant exhibition halls. There was a surprising lack of signage and, in such a huge place, we had to ask several times before we found the right area.

Having been given a large catalogue with a map and schedule of seminars we made our way into the exhibition halls. I guessed about 75% of visitors were using either a wheelchair or mobility scooter which made the aisles rather congested. There were several toilet blocks each containing only one accessible toilet but four more temporary accessible ones had been installed in an area behind the stands, including one Changing Places toilet. However these were also not well-signposted and took some finding. Considering over 10,000 people visited over the two days, this was not generous provision.

There was a selection of food and drink outlets offering sandwiches, pizzas, cakes etc., but a shortage of more 'healthy' options such as salads, veggie or vegan meals. If you wanted gluten free there was not much beyond Starbucks, so if you have particular dietary requirements it would be best to take your own food and drink with you.

Much of the exhibition seemed to be aimed mainly at professionals, such as those running carehomes, and people interested in buying a state-of-the-art adjustable bed. It was useful if you wanted to try a high-end mobility scooter or wheelchair - there were many different companies showing these.

Some of the products were really comfortable and stylish but very expensive. A small mobility scooter, which did have suspension (something I would love on Oxford's horribly uneven pavements and cobblestones) started about £2,300. I paid just £500 for my existing, non-suspension scooter.



There were a couple of holiday cottage rental companies, and stands for professional bodies such as Occupational Therapists, but I was disappointed not to find more small, useful aids for around the home on display. In fact, we only found three stands with small items. One was a very lightweight portable ramp, easily lifted with one hand - but, as it was made of carbon fibre instead of the usual steel, the price was £1,000. The second was an odd little tin can with crescent shapes cut into the lid, which was a finger nail file that could be used one-handed. Finally, some extra wide shoes and socks!

I suppose the cost of exhibiting was too much for sellers or distributors of smaller gadgets but it did seem a missed opportunity to see and try them. I was particularly interested in gadgets for the kitchen as we are about to make ours more accessible, but the only kitchen company there had nothing to show except standard cupboards that they could build to your requirements - as can most other kitchen suppliers.

There were many seminars taking place in smaller areas or theatres within the exhibition, but these were not easy to get into as about half the space was taken with chairs, leaving room for only a few people using wheelchairs or scooters. This meant people sat outside trying to hear and blocked the aisles. The range of subjects was very wide, from off-road driving for disabled drivers to neurological rehabilitation, or the future of Smart devices to the autistic brain. Many of the speakers were academics and several were from insurance companies or law firms specialising in personal injuries and compensation. The talks were no doubt very informative - if you could get in.

I came away pleased I had tried Naidex once, and with a variety of leaflets, but would not be in a rush to go again unless the range of products on display was wider.

Diane Sider



## Wolvercote Community Orchard

The Wolvercote Community Orchard was visited by Unlimited members Don O'Neal (electric wheelchair user) and John Wells (walking with the use of crutches) and the visit was hosted by Val Tate, Oliver Fyson, Clara Semple and Jo Malden from the WCO management group. The purpose of the visit by Unlimited was to review and assess the environmental access of the WCO and to advise about appropriate access changes needed for people with a range of physical disabilities and those with long-term health concerns that affect their mobility, so they are able to fully enjoy and participate in the WCO project.



The Wolvercote Community Orchard (WCO) is located on the Godstow Road near the Godstow Bridge in Lower Wolvercote opposite the Trout Inn, OX2 8PN. It runs adjacently along the length of the Trout Inn car park and is approximately rectangular, about 15m along the road, and about 60m perpendicular to the road.

It was created in 1994 by the Wolvercote Tree Group using a strip of allotments owned by the Oxford Preservation Trust. With kind permission from the Trust, the initial aim was to create an orchard in the village where you could find many forgotten, local varieties of apple. The first 20 trees were planted in 1994 with the help of the children from the Wolvercote Wildlife Watch Group and since that time they have gradually added more varieties as well as other fruit trees including plums, pears and quince. Now there are over 40 varieties of apple and over 60 fruit trees in the orchard.

The WCO has an annual Apple Day in October to celebrate the apple, which is attended by over 300 people. It allows the public to celebrate all things 'appley' and allows the public to enjoy the multitude of local varieties grown in the orchard along with games for children, apple juicing and much more.

[www.wolvercote.org/Tree%20Group/TreeGroup.htm](http://www.wolvercote.org/Tree%20Group/TreeGroup.htm)

It is also on Apple Day that the group pays the annual rent to the Oxford Preservation Trust in the form of a basket of apples.

It is a very picturesque countryside orchard, with many trees of different species. The trees are pruned to be low for easy fruit picking; this would even be possible from a wheelchair. The WCO is constantly being improved by the volunteer staff. The orchard is enclosed by a mixture of wooden and wire fences and a stone wall. In the middle of the WCO are a few benches and a well. At the far end of the WCO is a bee harvesting area, a shed, a composting area and a few rabbit-proofed wired-off areas of plants grown for the consumption of the bees.



Ideas suggested by Unlimited to improve access at the orchard include:

- putting signage on the road, perhaps a large board – like a pub sign. This would be useful to encourage the public to use the WCO.
- adding a laminated map near the entrance to give visitors an idea of the layout as soon as they enter the WCO and what is where.
- creating one gate that is 1.2 metres wide. The gate should open into the WCO and have self-closing hinges (the gate closes by itself). This would make it easier for a wheelchair user going through the gate, especially when leaving the WCO, as it is hard to close a gate behind you whilst in a wheelchair.
- making a dropped kerb level to the road from the gate.
- widening the path to 1.2 metres. A person using crutches to walk needs a wide path.
- labelling all plants and trees so visitors can be educated about the different varieties of apple trees and the variety of plants.
- having a few benches located around the inside perimeter of the WCO for people with mobility problems to sit down and rest.
- building a wheelchair accessible toilet in one corner near the wall alongside the road (when funds permit). The Stonehill Community Garden has built a wooden shack straw/ compost toilet for disabled people with ramped access. [www.stonehillgardens.co.uk](http://www.stonehillgardens.co.uk).

We thank the Orchard Committee members present for listening sympathetically to our comments, for being excellent hosts, and for thinking of asking our views before any construction had started. The Unlimited members would be happy to visit the WCO again if requested. Next time hopefully it will be a drier day!

Don O'Neal and John Wells

## Ministers outline plan for disabled people's air travel

New measures to improve air travel for disabled passengers are being considered by the government. They could include a limit on the time passengers wait for assistance boarding and disembarking, and quicker reunions with their wheelchairs. The issues faced by disabled flyers were recently highlighted by the BBC's Frank Gardner, whose wheelchair was lost at Heathrow Airport. He was kept waiting for two hours.



The government said it wants to ensure a 'positive' flying experience. Ministers are talking to the aviation industry about developing priority storage for wheelchairs so that they can be returned to their owners quickly upon arrival. They are also considering the removal of seats to allow wheelchairs to be used in cabins - allowing those who cannot transfer or who require specialist seating to travel - and to create space for disabled toilets. Mr Gardner welcomed these proposals but wasn't optimistic they would happen soon.

'As a wheelchair user, I have experienced so many problems that the mere thought of air travel causes a twinge of anxiety,' said Lucy Webster of BBC News. 'More often than not, my wheelchair is damaged. I have seen my precious motor (detachable, as the airlines like it) be flung with great force onto a pile of luggage, as if it were a bag of clothes and not my only means of independent movement. I cannot go to the toilet on the plane as I need a personal assistant to help me and the cubicles are too small, so I have not taken a long-haul flight since I stopped travelling with my parents. I wonder if I will ever fulfil my desire to see, as an adult, the world beyond Europe. The plans announced today would go some way to making my experience better. But they do not tackle the most degrading part of flying: the attitude of ground staff and cabin crew. I was once asked to get out of my wheelchair, just to make security's life easier. That particular problem will not be solved by more rules.'

The government is due to publish its aviation strategy in early 2019.

## Getting your health information in a format that suits you

How frustrating is it when the GP sends a letter and the print is too small? Or written with words and phrases too difficult to understand? Or you have told several health professionals that you are deaf but you always have to explain this at each appointment you go to?

Now all organisations that provide NHS care and/or publicly-funded adult social care are legally required to follow the NHS Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

So if you or a family member needs letters in Easy Read, or you need someone with you at appointments to help you communicate with the Doctor, or letters sent to you by email for your screen reading software then 1) Ask for this, 2) Make sure it is recorded on your notes and 3) Make a fuss it isn't.

## Council tax rebates for severe mental impairment

Did you know that if you or a family member has a Severe Mental Impairment you can get a discount on your (or their) council tax? Someone who has been medically certified as having a permanent condition that affects their intelligence and social functioning (such as Alzheimer's, but many other conditions apply) is 'disregarded for council tax purposes' in England, Scotland and Wales.

If the person diagnosed as SMI lives with just one other adult, the council tax discount is 25%. If the person diagnosed as SMI lives alone, the discount rises to 100%. Not only can you get the discount applied for the future but in some cases you can get a backdated refund. Do let us know if you succeed in getting a rebate from your district council and if you get it backdated. We would be interested to know which of the five Oxfordshire councils do this.

## West Oxford Wheelchair Dance group - WOWD

This group meets every Wednesday from 1pm to 2pm in the Windrush Leisure Centre, Witney. It is just for fun but if you are competitive then the training for the national competition is on Thursday. Everyone is welcome, whatever your ability and whether you have a manual, electric or para wheelchair.

07780 298534

mailto:[info@westoxwheelchairdance.co.uk](mailto:info@westoxwheelchairdance.co.uk)



## Meet the Member - Jo Driver

Jo first came across Unlimited when we had a stall at a mobility fair in Abingdon. Married in 1986, she has twins, a son and daughter in their early 30s and a daughter in her late 20's and four grandchildren. They all still live not too far away from their mum. Jo helps out with childcare along with looking after her five dogs.



'Why has no one ever invented a way of pushing a baby's buggy for a wheelchair user?' says Jo.

She now lives in Botley, caring part-time for her Mum in Radley. Jo is a wheelchair dancer and is just starting her training for the dance nationals in October organised by Para Dance UK. She belongs to West Oxfordshire Wheelchair Dance club, training once a week in Witney. The Witney club will be performing salsa and quickstep. Jo is doing a solo, a duo and is in the group dance, all in her manual chair. Her solo piece is to The Climb by Miley Cyrus – a song which means a lot to her.

Jo used to work full-time as a facilities manager even after a major fall downstairs in 2009. Although her company were very supportive Jo found managing her condition and medication wasn't compatible with work. Jo says 'When you manage a team it is not a good look when you doze off in a meeting!' She now volunteers with the charity Back Up which supported her after her accident. Jo took their 'skills for independence' course – everything you need to learn about getting out and about, driving a car and moving around your home independently. She has done a five-kilometre push for Back Up to raise funds and is now a mentor for people who are newly spinal cord injured. The mentor programme offers 10 sessions over the phone.

Jo has Cuada Equina Syndrome (CES) - a condition due to damage to the bundle of nerves below the end of the spinal cord. Symptoms include low back pain, pain that radiates down the leg, numbness around the bottom, and loss of bowel or bladder control. Jo has a lot of pain and has had a lot of surgery. She uses a wheelchair when she is out of the house and uses crutches in doors.

I asked Jo what was her biggest challenge with being a disabled person. 'A huge thing for me – when I am going somewhere new it takes me a lot of time beforehand to work out where to park and how to get to where I want to go. I use Google Earth to make sure there are no barriers and that there are kerb drops.

Even a little lip is enough to stop my front wheels. I have ended up in a bus lane before now.

Strangers are lovely but it is embarrassing to cause a hold up.' Jo says it really knocks her confidence. She wants to be independent, not relying on a travel companion, but it does put her off going new places on her own.

'Even in the brand new Westgate Centre some shop entrances have a lip which you have to get at just the right angle or there is a real danger of tipping. A shop like that loses out on my custom – I won't go in.'

Jo would like Unlimited to be 'the eye in the sky, to test out access and maybe produce access guides.' She would also like Unlimited to be better known so she is going to encourage the Wheelchair Dance group members to join us. She has also volunteered to do some access visits in Oxford city centre.

Back Up [www.backuptrust.org.uk/](http://www.backuptrust.org.uk/)  
Tel: 020 8875 1805 [admin@backuptrust.org.uk](mailto:admin@backuptrust.org.uk)

## The Herbert Protocol

A new tool to help find missing people with dementia was launched recently in partnership with search and rescue teams across the Thames Valley.

The Herbert Protocol is a form to record key information about a person with dementia. This should be completed by carers or family members in case they go missing. The Herbert Protocol initiative is named after George Herbert, a war veteran of the Normandy landings, who lived with dementia.

Memory problems are one of a number of symptoms that people with dementia may experience. This can lead to feelings of confusion, fear and vulnerability and consequently can result in a person going missing. Adopting the Herbert Protocol will help to ensure that the police and partner agencies, including the volunteer search and rescue teams, have the best possible information should someone with dementia go missing and a search is needed to find them. The form may include if the person is on medication, favourite places they like to visit or key people they know.

Det Supt Nick John, Head of Protecting Vulnerable People, said: 'I would strongly urge carers, whether family members, private carers, or care home staff, to adopt the protocol by completing the Herbert Protocol form in advance.'

[www.thamesvalley.police.uk/about-us/publications-and-documents/herbert-protocol/](http://www.thamesvalley.police.uk/about-us/publications-and-documents/herbert-protocol/)

## Email Victory for Larry

I wanted to escape from the problem of using a telephone call centre to communicate with DWP. At that time the calls were charged, and, because I used a mobile phone, I faced the probability of running out of phone credit as well as the possibility that my requests could not be met by a call centre operative. I wanted to be able to use email communication. This has a significant benefit insofar as it contributes both to clarity and certainty. An email provides a permanent record with a date stamp which proves the communication has taken place. An email records clearly, in writing, what was communicated by both sides. An email also records the amount of time elapsing between when my request was made and when a response has been received.



The DWP first agreed to remove premium cost phone lines but refused to grant permission for email communication. They then agreed that some applications could be made using paper forms which replaced lengthy telephone assessments. Eventually, it became necessary to issue a 'letter before action' in respect of further proceedings citing the relevant articles of the UK Equality Act which support examples where a reasonable adjustment was being denied people who needed them. At this point the DWP agreed to make a reasonable adjustment and to permit email correspondence. I have subsequently used email correspondence. It is clear that it will be some time before DWP will have a sufficient number of staff trained to respond in writing within a reasonable time frame. We probably have further to go in accommodating and empowering people with disability. At least the principle of not discriminating against us has been tested in law.

Larry Gardiner FRSA

## Celebrating ten years of freedom via the bus pass in Oxfordshire

In April members of Oxfordshire Transport & Access Group (OXTRAG), Oxford Bus Company & National Pensioners Convention/Oxford 50+ met at John Radcliffe Hospital West Wing to offer leaflets celebrating the freedom that the bus pass has offered local people. The Oxford Mail photographed the occasion and local radio sought interviews. In 2008 the government introduced a concessionary bus pass for people with a disability or aged over 60 years. This bus pass has also been a huge benefit to the wider society, as people contribute over £10bn worth of time & skill through volunteering in their local communities.

Keeping people independent and active is a key benefit of the pass. Travel reduces isolation and possibly the need for health care. Using the bus in cities & towns also helps keep pollution down. Unfortunately not all Oxfordshire residents have good access to bus services- especially in rural villages - so OXTRAG will continue to encourage more and inclusive services. Thanks however must go to our key bus operators for their cooperation and nationally respected work on inclusive travel in Oxfordshire. OXTRAG looks forward to another ten years of free travel for people. We always welcome newcomers to our quarterly open meetings.

[www.oxtrag.org/](http://www.oxtrag.org/)



Feelings of loneliness affect people of all ages and backgrounds and it can be difficult to admit to. The Archway Foundation was established in Oxford in 1982 to help relieve some of the real distress caused by loneliness. We connect those feeling alienated with a diverse group of volunteers, many of whom know for themselves how damaging loneliness can be.

Archway channels energy into action. We run social events and a befriending service. Unlimited members Pam and Bill Lipscombe have volunteered at The Archway Foundation for many years, helping to organise the many activities that are enjoyed by the clients.

The Archway Foundation

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