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Hearing  Link

Hearing Link

Matters

Issue 19 — Summer 2016

**Switching
on to
hearing loss**

p07

**Emily writes
NF2 memoir**

p04

**Hearing loss
blog guide**

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Hello and welcome to Hearing Link Matters



Welcome to our bumper 28-page Summer edition of Hearing Link Matters.

I'm delighted to share with you yet more inspirational stories about incredible individuals.

None more so than Emily Owen — a valued Hearing Link volunteer and now literary star. Her new book, 'Still Emily — Seeing Rainbows in the Silence' is a phenomenal read and I thoroughly recommend it. Read her story on **P4/5**, as well as a chance to win a signed copy of her book.

We also share the experiences of Tim Hardy and his hearing loss journey to receiving a cochlear implant on **P7**.

Folk musician, Rob Finlay, discusses on **P11** how he came back from the brink

after a Rabies vaccination brought on sudden hearing loss in his right ear.

We congratulate our Northern Ireland volunteer James Newell for being named the recipient of this year's Heather Jackson Award on **P25**.

And, we share the results of Hearing Loop Awareness Week from November 2015 on **P14/15**.

You can also find more about our specialist support programmes taking place across the UK over the coming months on **P20-23**.

Finally, you may notice additional adverts within this edition of our magazine which allow us to continue to produce this valued resource. We hope this selection highlights relevant solutions to changes in your hearing. If you would like to give us feedback on this, please email media@hearinglink.org to share your views.

Thank you for reading Hearing Link Matters.

Dr Lorraine Gailey
Chief Executive

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To contribute, advertise, or if you would prefer to receive Hearing Link Matters electronically, contact the Magazine Editor, by emailing media@hearinglink.org

Contact Us

Head Office:

27-28 The Waterfront
Eastbourne
East Sussex BN23 5UZ

Tel: 0300 111 1113

SMS: 07526 123255

Email: enquiries@hearinglink.org

Scotland Office:

The Eric Liddell Centre
15 Morningside Road
Edinburgh EH10 4DP

Tel: 0131 447 9420

SMS: 07564 916798

Email: scotland@hearinglink.org

Wales Office:

Enterprise House
Navigation Park
Abercynon, Rhondda
Cynon Taf CF45 4SN

Tel/SMS: 07753 220075

Email: wales@hearinglink.org

Northern Ireland Office:

23 Enterprise House
Enterprise Crescent
Ballinderry Road
Lisburn BT28 2BP

Tel/SMS: 07534 563451

Email: northernireland@hearinglink.org

Hearing Link Helpdesk

helpdesk@hearinglink.org

Tel/Text: 0300 111 1113 **SMS:** 07526 123255

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Still Emily

Emily was diagnosed with Neurofibromatosis Type 2 (NF2) when she was just 16-years-old, bringing with it many symptoms including hearing loss. She is now sharing her experiences through her new book 'Still Emily — Seeing Rainbows in the Silence'. Here she explains what inspired her...

“ I picked up my flute and walked into the examination room.

The examiner, unsmiling, pointed me to a music stand in the middle of the room. He told me to begin.

Placing my music on the stand, I raised my flute to my lips. Inner voices jostled for my attention.

My child-self: 'I want to learn to play the flute.'

My music teacher: 'You've got real

talent.' My conscience: 'You should have practised more.'

The impending scales, my nemesis, mocked me.

The approaching aural tests, 'free points' for me, reassured me.

As did the sight reading.

The examiner cleared his throat.

'Begin your first piece whenever you're ready.'

I was always ready as far as music was concerned!

And so I began to play.

After a few weeks, the results arrived: I'd passed. More than passed, I'd done well. But not as well as I should have.

Next time, I told myself. Next time I'll practise...

One day, five years later, I woke up in a world of silence. ”

This is how my book begins.

'Still Emily — Seeing Rainbows in the Silence' has been a long time coming; but better late than never, it was released on May 11th this year.

Still Emily is about a journey — my journey.

When I was growing up, during family trips, my Granny always used to say: 'Let's make the journey part of the holiday.'

Our destination may be Malta, Devon or wherever, but let's remember that how we get there is part of the experience.

In no way am I suggesting that NF2 is a holiday, but it has brought with it a destination, an aim. For me, that aim is to not lose sight of myself.

In amongst the whirlwind of symptoms, operations, losing my hearing; it is easy to forget that I am still Emily. But, somewhere in there, I am. How I get to that point is part of the experience.

As with any journey, there are times when things are good. I can sit back, relax and enjoy the scenery.

There are also times when things are not so good. Times when other passengers crush me, or I feel sick, or I need to stop and get out or I'm fed up.

“ My sisters came to visit me as often as they could, their days becoming a routine of school, hospital, bed. School, hospital, bed.

Pollyanna, the youngest, was nine and very keen on jokes. She would arrive, pull out her joke book and jump up onto my bed, ready to read to me.

She often had to be moved quickly as she invariably ended up squashing one of the tubes to which I was attached — drip, catheter, or drain.

Undeterred, she would rearrange herself, open the book and launch

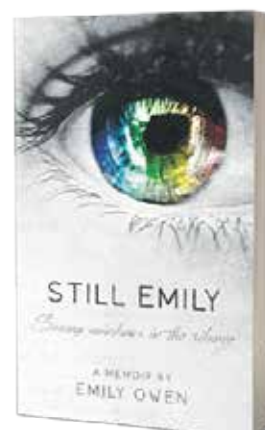
into regaling me with jokes. One of these jokes particularly sticks in my mind:

'Knock knock (Who's there?)

'Owl. (Owl who?)

'Owl you know unless you open the door?'

Pollyanna and I found this hilarious. She, because she was nine. I, because she was my baby sister. I remember





Emily Owen has published a book about her NF2 experiences

how hard it was to concentrate on what she was saying. I remember the effort it took to laugh in the right places. But mostly, I remember that she was there.

"Knock knock. (Who's there?)

"Emily. (Emily who?)

"Emily...umm...that's a very good question."

Who was this person lying in my hospital bed; head bandaged and unable to move? Who was she? And how was I ever going to open the door and find out?

And that's what 'Still Emily' is about. The good times and the bad times. The jokes and lying in bed unable to move.

It's about my life and plans being knocked down time and time again, but me learning to open that door and find that I am still Emily. It's still me inside.

“ (After an operation) I woke up and I realised what silence means — what it actually means. Not what my hearing self of yesterday had imagined it might mean.

Silence. Nothing..... **”**

Finally, I truly appreciated my hearing. All my life I had accepted hearing as just a part of who I was, but part of me had been taken from me.

Appreciation came too late. My hearing had gone — forever — and I didn't recognise this person whose ears didn't work. This person surrounded by sound, but hearing nothing. Nothing — I was terrified.

On a journey, stopping to sort a problem is not necessarily a one-off. Just because you get out and stretch cramped legs once does not mean you won't need to do so again.

Similarly, finding that I am still Emily is an

ongoing process. A determination not to let my NF2 and deafness define me — whatever life throws my way.

A determination to find the positives, however big or small — and sometimes the 'only' positive is chocolate. Which, to be fair, is actually quite a big positive!

'Still Emily' is available to buy online from Amazon and other retailers. <https://www.amazon.co.uk/Still-Emily-Owen/dp/1910786438>

For more articles from Emily, visit www.emily-owen.co.uk

Win a signed copy

One lucky reader can win a signed copy of 'Still Emily'. To enter, simply send your name and address by **31st August 2016** to: 'Still Emily' competition, Hearing Link, 27-28 The Waterfront, Eastbourne BN23 5UZ.



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Hear now. And always



Switching on to hearing loss

Having lived with steadily worsening hearing throughout his adult life, in 2014 Tim Hardy entered a still more challenging world of total silence.

Tim's hearing difficulties first emerged 40 years ago at university. Diagnosed with bilateral otosclerosis and sensorineural hearing loss, from the age of 22 he depended upon hearing aids to pass through law college and beyond into a legal career.

Despite reliance upon the most powerful aids and self-taught lipreading, as his hearing loss became more and more severe, Tim struggled in his personal and professional life — a struggle often silently endured.

As a practising partner in a large city law firm, there was little scope for taking refuge in books, solitude, or leisure activities. He said: "A theatre outing or visit to a pub can prove surprisingly solitary if you alone are missing the dialogue."

Tim was fortunate to be able to rely upon his wife, Angela as his interpreter and prop. Yet, despite all her help, too often he experienced life as a spectator. When efforts at corrective ear surgery were finally exhausted, Tim entered a world of potentially indefinite silence.

A colleague introduced Tim to Hearing Link and our five-day Intensive Rehabilitation Programme; and soon he and Angela enrolled on the first available course in Nottingham.

First impressions were very positive. "I think we both learnt more in those few days than over as many decades. Not just how to cope with hearing loss, but how positively to take control of its impact on one's everyday life," he said.

The IRP gave them a fresh perspective, boosting both Tim's confidence and Angela's understanding.

"We found ourselves able to take charge of issues, rather than struggling



Tim Hardy

to react as we encountered problems. Above all, I am most grateful to Hearing Link for making me realise properly that the mistake many of us make is to concentrate far too much on the loss or the hearing rather than the real issue of importance: the art and science of communication," Tim said.

Switching on to the real significance and impact of hearing loss was every bit as momentous as the subsequent switch-on of Tim's cochlear implant.

With the support of his GP and Hearing Link, Tim enrolled with the Cochlear Implant Programme at the Royal National Throat Nose and Ear Hospital in London.

In February 2015, he was fitted with a Cochlear Nucleus C124RE implant in his right ear, together with a Cochlear Nucleus 6 CP910 Sound Processor.

Six weeks later, his cochlear implant

was switched on. "My circumstances could not have changed more quickly, fundamentally or dramatically!

"I didn't simply return to the world of sound, but I was catapulted back into a rich, three-dimensional world of sound I'd last heard over 30 years previously."

Now, over a year on, Tim can again enjoy life and recorded music, using the telephone, TV and cinema without subtitles and recently, for the first time, theatre without captioning.

"My cochlear implant has trumped every aid or benefit I have derived in over 40 years of deafness bar none!

"The first 'switch on' by the IRP was of our capacity to cope and was every bit as valuable as the second CI 'switch-on' of my capacity to hear once again.

"Hopefully the benefits of the CI will prove enduring. Those of the IRP most definitely shall," said Tim.

Ask the Panel

Dear Hearing Link,

I was recently diagnosed with a sudden hearing loss and my ENT specialist has since confirmed that my loss will be permanent in one ear.

As a classical pianist and lover of all types of musical hobbies such as going to a theatre, dancing and listening to the radio or MP3 player, I'm worried that my hearing loss will signal the end of these.

I have been told by a private hearing aid dispenser that there are higher level hearing aids, and potentially equipment out there that will allow me to continue with my interests, but I am unsure where to begin.

I also don't know what to expect from hearing loss: how will this affect conversations and will I hear any day-to-day sounds differently because I use hearing aids?

Reginald, Liverpool.

Ann Thallon



Ann has a moderate/severe hearing loss and tinnitus which began in her thirties.

Hello Reginald,

Coming to terms with sudden hearing loss inevitably raises countless questions. There will be much to try out and explore, but be assured, you already have a very musical brain and all that you have inside you will not disappear.

However, your brain may need time to adjust to hearing and sensing music in a different way. The Hearing Link website has many inspirational stories of musicians experiencing deafness. Check

out: <http://www.hearinglink.org/your-hearing/sudden-deafness-hearing-loss/sudden-deafness-hearing-loss-stories-videos/>

Additionally, benefit from the experience of others – including musician Richard Einhorn, in his article 'Observations from a Musician with Hearing Loss': <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4040854/>

Also, musician Rob Finlay's story on P11 of our magazine will be an interesting read.

On wider issues, can I recommend asking for a visit from a Hearing Link Community Support Volunteer, with whom you can talk in depth about challenges and possible ways forward?

Attending one of our specialist programmes will also put you in touch with others and help you manage your life with hearing loss. You have a journey ahead, Reginald, but you are far from alone.

Ann

Margaret Canning



Margaret has sensorineural hearing loss which has deteriorated over the last 20 years. She now has a cochlear implant.

Dear Reginald,

I'm sorry you've been diagnosed with sudden hearing loss. I understand how upsetting this will be for you.

However, with the right assistive devices and support you can continue to enjoy the things you love doing.

Quite a few theatres have loop systems and by turning your hearing aid to the T-setting, you will be able to hear what is being said. Most theatres also have captioned performances and the ticket

price is often reduced for deaf and hard of hearing people.

A Streamer Pro can be used with an MP3 player and make listening to music possible — you can also try a Personal FM system.

Have you thought about joining a lipreading class? I've been going to classes for some time and it is one of the best things I did.

You'll also meet people in similar situations, and share tips and

experiences. With regard to everyday sounds, it depends on your level of hearing loss. There will be things you'll be able to hear better than others.

You may find high pitched sounds a problem, e.g. loud pubs and restaurants, etc. However your audiologist can help by adjusting your hearing aids to suit these situations.

I wish you the best of luck.

Margaret

Jack Sandover



Jack is a retired academic and has been severely deaf since his fifties.

Dear Reginald,

I'm sorry to hear about the sudden change in your hearing. However, be positive – there are usually ways and means.

You can certainly get 'higher level' hearing aids that will boost your hearing in your bad ear, even if the loss is severe.

However, this may involve 'frequency shifting' so that you hear higher pitch sounds better and, in my experience, leads to a general change in tone compared with the good ear.

I imagine that for you, a musician, any difference in tone between ears would be unacceptable.

However, unless you are a critical stereo sound listener you may find

that your good ear does a very good job of listening to music. To appreciate recorded music you would benefit from a 'dongle' such as the Oticon Streamer.

These devices allow you to send music directly from a player (e.g. MP3) to your hearing aids via a cable or Bluetooth. The resulting sound is very good.

To begin with I suggest you look at product suppliers such as Connevans or the Action on Hearing Loss website to see what is available and then discuss it with them.

It is most likely that your hearing loss will make conversations in a noisy restaurant or at family gatherings difficult. It's the first problem brought up when I meet up with hearing impaired people.

However, with good hearing aids you

should find that most conversations are OK with practice.

You may find day-to-day sounds different, but you get used to that. Already your perception of these sounds is probably different to what it was before your loss.

I would also suggest that you try to meet up with others with hearing loss, such as a lipreading group.

Attending can help speech understanding, but also deals with communication strategies and equipment generally.

You will soon find that you are not alone with your hearing loss and your confidence will be boosted.

Jack

Quick Questions

James Newell



James is a cochlear implant user who will make you feel at ease about your hearing loss.

Q. I've had hearing loss for three years, but never been to a lipreading class before. What benefits are there from attending one?

There are great benefits from attending a lipreading class. Firstly, to learn why so many things can be misunderstood can be uplifting to know that you are not the only person. It is also an opportunity to socialise in a safe environment with other people with hearing loss, which can work wonders for your confidence. There is so much knowledge to be gained from attending a class whether it's lipreading skills, equipment, hobbies, or encouraging each other to try out new things.

Q. What types of equipment would help me to enjoy TV again? I'm very isolated without it.

If you have hearing aids that are loop compatible, you can get a hard wired loop system in the home which

will allow you to tune into the TV without having the volume raised. There are so many different options available, headsets, neckloops, bluetooth devices; so I would recommend contacting your Local Health Authority for advice and information. I would encourage you to try out different devices to see which suits you best, so you would be trying before buying.

Q. Is hearing loss classed as having a disability or does it entitle you to any benefits?

Having a hearing loss does entitle you to benefits, such as Personal Independent Payments (previously known as Disability Living Allowance), discounts on public transport, Cinema Exhibitor Association card for the cinema and much more. It would be worth contacting the Benefits Advice Centre in your local area for more information.



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Life sounds brilliant.

Half-Heard

Rob Finlay was a singer-songwriter and filmmaker, loving life and looking forward to travelling to Peru to make a documentary about Pink River Dolphins in the Amazon. But a Rabies vaccination he received ahead of his travels in 2014 brought on agonising tinnitus and he woke the next day to find he'd lost his hearing in his right ear.

"It was frightening and baffling. I went straight to the doctors where they tested my hearing with a tuning fork; both air and bone tests confirmed that I'd lost my hearing," Rob recalled.

A friend encouraged him to go to his local hospital in Essex that day for immediate medical attention. Doctors prescribed steroids to reduce the inflammation and dizziness.

He was diagnosed with Sudden Sensorineural Hearing Loss caused by the vaccination, which is very rare.

Rob's recovery took months and four months after his diagnosis he was fitted with a hearing aid which made life easier for him.

His hearing loss impacted on his musical career, robbing him of the chance to play live.

Despite this Rob, now 34, has remained positive by writing about his experiences. He also sought information about hearing loss through forums, blogs and Hearing Link's website www.hearinglink.org.

Rob said: "I spent a lot of time searching for information, and because the information was so varied and often terrifying, it was good to find Hearing Link where there was sensible information in one place.

"Reading the forums and articles on the site reassured me and helped to give me an insight into a world that I had never really considered. I was terrified for the first couple of months and very depressed for at least six months.



Rob Finlay

Hearing Link helped me get through those tough times."

A year after losing his hearing, Rob's confidence slowly began to return and he re-immersed himself in his music.

Rob said: "My hearing loss really stopped me in my tracks. I was just starting to play big gigs and festivals, and was building momentum in my career. It took me out of action as I had to cancel gigs.

"Nearly two years on, I still haven't returned to the circuit and playing live and rehearsing is difficult for me. Instead, I've concentrated on writing and I recorded my new EP HALF-HEARD which was a great experience.

"I loved working in the studio and being creative. It's always hard work, especially when you are trying to cram in a lot with a limited budget. The EP's title is certainly inspired by my

hearing loss. I hear everything from one side of my head now. It's a kind of double-edged title because I feel that as an independent artist these days it's incredibly hard to get heard above the noise of commercial music. Many people don't really listen to music like they used to and I think that's sad."

Rob hopes to secure a publishing deal for his material and will continue to write and record. He might even write directly about his hearing loss journey.

He said: "The most important thing for me is to continue to develop my song writing skills. Great songs tell a story and you never know what life's going to throw your way for your next lyric."

To find out more about Rob or to download his album, visit <http://robfinlay.co.uk>

Lipreading

Local group spearheading lipreading provision in the West Midlands

When Government cuts three years ago left Coventry and Warwickshire areas without lipreading classes, three local students stepped in to fill the gap.

They organised themselves into a charitable trust, now called the 'Central England Lipreading Support Trust' (CELST) and raised enough money to continue the classes and find new lipreading tutors.

As a result, the organisation is running classes in Coventry, Leamington Spa, and Kenilworth for any adult in the area who feels it could benefit them.

The classes have been extremely well

received with one student saying: "I enjoy the lessons because they are fun and interesting. It is good being with people who understand the difficulties and frustrations of being deafened."

The Trust is also discovering that, as well as directly benefitting the students through training, it's also creating priceless bonds between the participants, encouraging communication amongst people who have lost the art or will to socialise.

The Trust recently organised informal gatherings at a local coffee shop where students could meet old friends and make new acquaintances.



CELST lipreading class

These have proved a hit and have been scheduled as a monthly event.

To find out more about CELST visit www.celst.org.uk or email info@celst.org.uk



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Which blog?

Hearing loss, at any level can be a lonely experience. However, there is a wealth of information out there on the internet from charities, organisations and individuals who blog. Our volunteer Laura Lowles has been finding the best ones...

About Laura

Laura, 29, has been a Med-El Cochlear Implant user since December 2014. She was born with significant bilateral hearing loss due to maternal rubella, but in February 2014 suffered from Sudden Sensorineural Hearing Loss which dramatically decreased her hearing to the profound range. Laura is passionate about raising awareness of hearing loss.



Hearing loss at work

Hear2Work launched in November 2015.

Its creator Tracey Sharp is passionate about helping people with hearing loss manage their day-to-day lives in the working environment.



She not only provides helpful advice and tips, but shares reviews of assistive devices and personal stories.

Tracey has first-hand experience of hearing loss and shares her experiences to save you the hassle of all that research.

You can find her blog at: www.hear2work.com

Young adults — hearing loss

'Day in the Life of a Deafie' is by a 19-year-old female named 'E' who has been profoundly deaf since birth.

She is also a freelance writer and aspires to be an ambassador for deaf people.

She blogs about family life, deaf news, her daily struggles and the odd teenage drama. This blog is perfect for teenagers who struggle with feeling a little bit 'different' from their hearing peers.

Read more at: www.dayinthelifeofadeafie.wordpress.com



Tinnitus

'Whooshers' is a forum and information centre for those with pulsatile tinnitus.

This form of tinnitus is when the individual hears a constant and rhythmic whooshing, pulsing / pulsating sound in sync with their heartbeat.

Emma Greenwood set up the website with two other "whooshers". It includes personal stories, useful links and tips and advice on how to deal with the condition.

Get involved at: www.whooshers.com



Hearing loss, tinnitus & cochlear implants

This article wouldn't be complete without a little shameless plug for my own blog: 'The Invisible Disability and Me'.

It's my personal blog about my journey through Sudden Sensorineural Hearing Loss, coping with tinnitus and cochlear implantation.

I aim to raise awareness of Sudden Sensorineural Hearing Loss and hearing loss on the whole, and provide helpful tips and hints for coping with different situations.

Read my posts at: www.theinvisibledisabilityandme.co.uk



Getting the UK in the loop

Last November, more than 300 volunteers joined forces across the UK for Hearing Loop Awareness Week. Their goal was simple – to find out how good hearing loop provision was in their local communities. Here, we report on their findings...

Hearing Loop Awareness Week was born out of our wider Let's Loop the UK initiative.

This launched in 2012 with the aim of providing more working hearing loops in public buildings, venues and shops across the UK.

Often hearing loops are absent, don't work properly, or staff simply don't understand how to switch them on or use them.

This leads to hearing aid users losing confidence in this essential technology and feeling excluded from daily activities.

In early 2015 our initiative took off with 10 active Let's Loop groups running in communities across England.

Before Hearing Loop Awareness Week, these groups had carried out up to 200 audits in their local communities and campaigned for better provision.

However, Hearing Loop Awareness Week was a chance for them and others to go one step further and raise awareness of this technology.

It was an opportunity for a dedicated week of loop checking, helping us build the most accurate picture of hearing loop provision to date and also to discover their overall quality.

Who was involved?

More than **300 volunteers** from every country of the UK took part, carrying out a phenomenal **732 audits**!

We also had backing from Rotary International, Barclays, The National Trust, and manufacturers including Contacta, Deaf Alert and Ampetronic.

Justin Tomlinson MP, Minister for Disabled People also publicly backed the campaign, saying:

"Hearing loops are a vital tool to ensure communities reach out to everyone and also have clear business benefits – they help companies grow by becoming more accessible to a greater number of customers."

What type of premises were audited?

Many different types; however most of our surveys were carried out on local high streets throughout the UK.

Pharmacies accounted for **17%** of venues audited, the second most audited were **banks (14%)** and in third place were **supermarkets (13%)**.

However, public buildings such as council offices, police stations, libraries and cinemas were also checked.

What did our volunteers find out?

Unfortunately our findings were consistently poor. It confirms that

progress to provide more good working hearing loops is a painfully slow process and much more needs to be done.

Of the **732 venues** audited, **24%** were found to not have a hearing loop installed at all.

76% were found to have a loop installed, but most were not working properly. **31%** were portable loops which is rarely a satisfactory solution, while **30%** were not working at all.

Volunteers also rated each venue out of five on three quality factors – quality of the hearing loop, staff knowledge and signage.

The average scores, with 1 being poor and 5 being excellent, were:

- 2.5 – Quality of hearing loop
- 2.6 – Quality of staff knowledge
- 2.8 – Quality of signage displayed

What next?

The results from Hearing Loop Awareness Week have since been shared with businesses across the UK and we are working in partnership to improve their service for customers.

This includes Boots, which has since worked with our Let's Loop Swindon group to highlight areas of improvement required in its stores across the town.

Justin Tomlinson MP has also written to every major supermarket and pharmacy chain to encourage them to listen to calls to improve their provision.

He also backed a video created by students in Swindon which highlights difficulties faced by hearing aid users.

For full results from Hearing Loop Awareness Week, visit www.letsloopnow.com

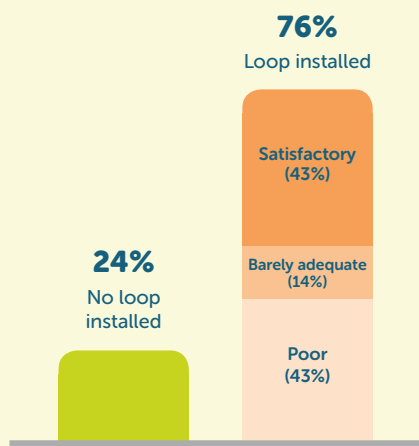




Volunteers from Let's Loop Chester during Hearing Loop Awareness Week

Results: At a glance

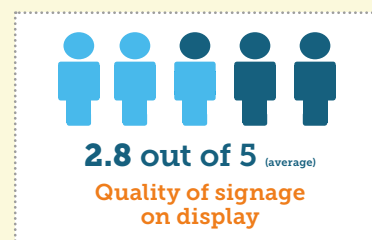
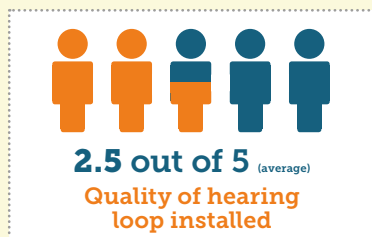
Provision of hearing loops



Of 556 loops installed, our volunteers found:

- 43% were poor quality
- 14% were barely adequate
- 43% were satisfactory

Quality ratings



What our volunteers said

“

The staff at the pharmacy had very basic knowledge, but had never used the hearing loop before.

Very helpful staff who knew how to work the loop and the mic.

Frustrating! The loop was not working despite signage being displayed.

”

signia

Life sounds brilliant.

Welcome to the colours of sound.



After 130 years of innovation, our heritage speaks for itself.
In future, it will say Signia.

Continuous innovation calls for passion, courage and forward thinking. With our new brand, Signia, we continue to challenge the impossible. Customer centered in everything we do, our focus is on making a difference to our customers and helping them listen to what matters to them. Quality driven, the highest levels of reliability, accuracy and usability are vital prerequisites for all Signia products.

The vision of Signia combined with the experience of Siemens gives you a comprehensive portfolio of advanced hearing solutions and the support of a passionate team.

With Signia, the future of better hearing is in our hands. Let's make a difference together and, for even more people, ensure that life sounds brilliant.

Find out more about Signia under
www.signia-hearing.co.uk

Hearing
Systems

SIEMENS

Let's Loop: celebration event

Our Let's Loop the UK campaign has been incredibly successful since it started in 2012. With 10 active groups and two valuable Hearing Loop Awareness Weeks, we invited those at the heart of the campaign to a celebration event at the National Trust's Mottisfont property in Hampshire.



Photographs
© National Trust /
James Dobson

The progression of Let's Loop the UK campaign has been startling since its inception in 2012.

Its aim is to improve the standard of hearing loops in the UK and ensure everyone knows how to use them so that hearing aid users can have easy, relaxed exchanges when they most need them.

A number of very active Let's Loop Groups have been working throughout England in the past four years, and recently a National Steering Group was set up to provide coordination and consistency across all groups.

On 22nd June, the National Trust kindly hosted our event at their Mottisfont property in Hampshire to celebrate the success of this campaign so far, and bring together key players from our groups in the south of England to discuss plans for the bright future of the campaign.

On the day, a number of group members presented an overview of how their groups started, and the factors that contributed to their success.

They were joined by some of our partner organisations, including Boots, Rotary International, Swindon Borough Council, and the National Trust — all of whom spoke about their reasons for working with us.

Towards the end of the day, we held a discussion session which looked at some of the materials being developed to support the Let's Loop Groups, such as a new step-by-step guide due to be launched in the autumn.

We also explored how to increase awareness about loops and their value amongst hearing aid users in the community.

Our Chief Executive, Dr Lorraine Gailey, said afterwards: "The tremendous energy, enthusiasm and commitment

of so many different people involved in this campaign was inspirational. It is clear that Let's Loop the UK has hit the spot, and will continue to grow and achieve greater impact as time goes on."

Following the success of this event, Hearing Link will also be working with our other Let's Loop groups across the UK to gain their input on how Let's Loop the UK moves forward.

STOP PRESS!

As Hearing Link Matters went to print, we were delighted to learn that we've been awarded a grant by the Esmée Fairbairn Foundation towards our loop project. Hearing Link will receive £197,000 over three-years to support our campaign right across the UK.

Products at your fingertips

Did you know Hearing Link offers a range of solutions that could support the every day challenges of hearing loss? Our online shop stocks everything from badges, to wristbands and now assistive equipment. Here, we introduce some of our most popular items...

Communication resources

We have developed products, ranging from discreet to visible, which can help you to let others know what you need from them when communicating.

You can choose the products you feel most comfortable with and that help you to enjoy easier communication when you're out and about every day.

Items on sale start from as little as 75p (excluding postage) and include **badges, wristbands** (hearing loss

and lipreader options available), **communication cards, stickers** and **magnets**.

You can also save money on multiple products by buying our **Personal Awareness Kit (PAK)** which is ideal for when you are travelling and staying in hotels or staying in hospital overnight.

More solutions are available by visiting shop.hearinglink.org, alternatively please email shop@hearinglink.org.



Wristbands

New for 2016 — useful devices



Conversor Pro

Living with hearing loss can bring with it difficulty enjoying hobbies, pastimes and the company of others, but there are many solutions that can improve your quality of life.

We have teamed up with equipment provider Conversor to offer its range of assistive technology that is simple to use, adaptable to situations where sound can be an issue and suitable for many budgets.

Our selection of items will help you get the best from your hearing aids, participate fully in social activities, keep up in your professional life or relax in your leisure time.

Whether you want help to perform your daily tasks more easily or return to enjoying aspects of life that you have started to find a bit more difficult, there will be something for you.

Products include the **Conversor Pro**, **TV Pro** and **Inductive Neck Loop**.

Other devices available on our online store include our **LCD Boogie Board e-Writers** which are available in three different sizes and colours, starting at £19.99.

LCD Boogie e-Writer



Inductive neck loop



Personal Awareness Kit (PAK)

Ear protection and care

Our new range of products now also includes ear protection and care.

We are delighted to offer two products which will allow you to care for your hearing aids.

The first is the **OtoVita Drying kit**. This care set kit allows for the external disinfection and drying of hearing systems and earmoulds.

The pack includes cleaning tub, drying tub, drying tablets, air puffer and cleaning tablets. Our price, excluding delivery, is £14.99.

Alternatively, we have the **Easycare Hearing Aid Care Kit** priced £14.99 which is designed for all hearing instruments and all sizes of hearing aid batteries. It could help prevent costly breakdowns or repairs.

Finally, we also offer a range of **non-custom earplugs** which are suitable for all the family.

Visit shop.hearinglink.org for further information.

OtoVita
Drying KitEasycare
Hearing Aid
Care Kit

Did you know

Hearing Link members are eligible for a 10% discount off shop products.

Discounts can also be applied to bulk orders.

For more information please email shop@hearinglink.org

For our full range of shop products visit shop.hearinglink.org (No VAT is charged on our products)

England update

Link Up Programmes set for the Midlands

We will be hosting four Link Up Programmes in the Midlands during 2016 in the second year of our two-year project funded by the Big Lottery Fund.

They will be held in **Derby (2nd & 3rd July)**, **Kidderminster (16th & 17th July)**, **Leicestershire (3rd & 4th September)** and **Warwickshire (24th & 25th September)**.

The course offers a fantastic opportunity for individuals and their partners to look back on their hearing loss journey, to learn new skills and connect with others with similar experiences.

Led by Hearing Link's experienced volunteer facilitators, participants will explore hearing loss issues in a safe and supportive environment.

The Link Up Programme, which is fully funded and free to attend, is held across a weekend, with Saturday night accommodation and evening meal available to all participants.

Partners and family members are encouraged to attend, as



there is a great deal of information and tactics to be gained from attending.

Recently our Link Up volunteers (pictured above) met in Birmingham to plan the forthcoming programmes.

To find out more about the programme, or to book your place, visit: <http://www.hearinglink.org/services/link-up-programmes> or email helpdesk@hearinglink.org.

Action plan on hearing loss

There are prospects of improved audiology services in England following the publication of the **Action Plan on Hearing Loss** by the Department of Health and NHS England last year.

The action plan is now being implemented, and five Task and Finish groups have been set up to ensure that it brings about real change.

Hearing Link is represented on two groups — 'Early Diagnosis and Intervention' and 'Living Well with Hearing Loss'.

We aim to ensure that the interests and issues of adults with acquired hearing loss are fully represented in the

discussions and recommendations. In June 2016, a debate was held in the House of Commons on the topic of hearing loss, which demonstrates that the issues are being taken seriously at a high level.

This preceded the launch of the new Commissioning Framework on adult audiology services which offers guidance for Clinical Commissioning Groups across England.

Hearing Link and many other voluntary bodies had a significant input into the framework through the Alliance on Hearing Loss and Deafness.

The strength of the voluntary sector

voice in helping to shape both of these is very encouraging as we are exerting more influence on shaping services than ever before.

Commissioning decisions are still made at local level for all health services in England, and for that reason, it is vital that you take an interest in any local planning or consultation meetings that are being held in your area.

For more information on how you can become involved, visit <https://www.england.nhs.uk/ourwork/patients/>

To read the Action Plan on Hearing Loss, visit: <https://www.england.nhs.uk/2015/03/hearing-loss/>

Scotland update

Residential Self Management Programme

Our highly-regarded Self Management Programme is returning to Scotland in 2016, with three courses set to take place between September and November.

The programmes will be held in **Glasgow (2nd-4th September)**; **Edinburgh (28th-30th October)** and **Dundee (25th-27th November)**.

In a change to our recent Self Management Programmes, which took place one day a month for three consecutive months these programmes, supported by The Alliance Scotland's Self Management Impact Fund, will be held over the course of a weekend.

Each programme is free to attend and family members or friends are encouraged to take part with participants. Accommodation and meals will be provided, however travel to and from each venue is not included.

The Self Management Programme, which is for adults with any level of hearing loss, offers a range of useful techniques



Programmes will take place from Sept-Nov

and strategies to enable people with hearing loss to feel independent and more self confident.

Workshops include managing frustrations, communication, equipment, relaxation and personal safety.

If you would like to attend any of our 2016 programmes, email scotland@hearinglink.org or call 0131 447 9420.

Hear & Now event success in Scotland

Last year, we hosted two Hear & Now events in Scotland, offering information and support to more than 120 people with hearing loss, their families and friends.

The events were held at the Royal Botanic in Edinburgh (October) and The Lighthouse in Glasgow (December).

Attendees had the chance to learn about different types of technology such as hearing loops, listen to inspirational stories from individuals supported by Hearing Link and find out more about the types of services our charity offers throughout Scotland.

It was also an opportunity for them to meet others with similar experiences and find out about services and classes available in their local communities such as lipreading and accessible cinema.

We would like to express our thanks to the Alliance Scotland, John Curtis, our exhibitors and Scotland volunteers for supporting these events.



Hear & Now Glasgow speakers



Volunteers George & May

Contact Hearing Link in Scotland. Email scotland@hearinglink.org, call 0131 447 9420 or text 07564 916798

Wales update

Lend me your Ears conference

In April, Bangor University in North Wales hosted its fourth one-day conference for people with hearing loss and their families called "Lend Me Your Ears" or "Clust i Wrando" in Welsh.

Its aim is to bring together individuals with hearing loss, their families, friends and interested professionals to socialise and share information and experiences on a whole range of topics relating to hearing loss and D/deafness.

Our Wales Manager, Wendy Marshall, was one of four speakers and talked about how powerful the support of peer volunteers can be for people dealing with the daily challenges of hearing loss. The talk was followed by questions and discussion about our work.

Volunteers and staff from a variety of other organisations were on-hand to offer support and information at display stands throughout the university's beautiful Powis Hall.



Wendy chats to conference delegates

Welsh language leaflet

We are delighted to have produced our most recent publication in the Welsh language.

Our information leaflet "Hearing loss: specialist support" explains how we can connect people through a variety of group programmes and one-to-one contact in all four countries of the UK.

2,000 copies have been printed, so if you live in Wales and would like to stock our leaflets bilingually, contact us at wales@hearinglink.org for more information.



Link Up Programme held in South Wales

We ran our first Link Up Programme in South Wales in November last year funded by the Moondance Foundation.

This two-day session, held over a weekend, was a great opportunity for previous Hearing Link programme participants to reconnect with old friends, meet new ones and reflect on how far they have come.

We also welcomed a small number of new participants to join us for a "taster" session on the Sunday.

Our volunteer facilitators explored with the group a wide variety of topics and challenges; and there were plenty of opportunities to meet other people on the programme and learn from



each others' experiences. As with all our programmes, partners and family members were welcomed.

We were delighted to have 14 people on our first "reunion" event. We hope to run a similar event in North Wales to give more people the opportunity to re-connect or to meet us for the first time.

Join in our activity in Wales. Email wales@hearinglink.org or Tel/SMS: 07753 220075 to find out more.

Northern Ireland update

Connecting with each other

We have been making our presence felt across Northern Ireland in many different ways during 2016.

Our volunteers have been connecting with people and making their mark in fresh and unmissable ways.

Known as the 'NI Hearing Link Minions', they have been hard at work preparing for events and programmes.

We successfully delivered our fourth Self Management Programme in Bangor, Co. Down. This was a new area for us at Bangor Abbey Parish Hall, with superb catering from Sunflower Sandwich Bar. These connections allowed us to make new friendships which we hope to build on.

The Banbridge Lipreading Group also completed its third season with a total membership of around 15 people. Les and Ramona Williams continue to lead this group, with Anne Madill as the Tutor.

Fundraising events are being held during the summer, such as car boot sales and social evenings.

Other volunteers have been actively promoting Hearing Link in their local areas with a view to building stronger partnerships.

In June, we had a lovely evening of fun and sharing in Belfast. This brought together some of those who have benefitted from all our activities. The



Northern Ireland's Hearing Link Minions at work

evening was facilitated by five of our volunteers who invited everyone to share their experiences of Hearing Link to date and their suggestions for future events.

It was a great evening and we hope to help more people connect in similar ways over the coming months.

Community fundraising

Our community fundraising efforts were greatly supported by a fun and challenging Table Quiz, organised by a family who attended our Newry SMP last year and who benefitted from the Banbridge Lipreading Group.

Gail and Nick Rusk, with their son Ethan, raised £480 and at the same time managed to outwit some of the most seasoned Table Quizzers at their event in Portadown! Sincere thanks go to the whole family for their energy and time with this fundraising initiative.

We are also grateful to a number of local funders who have supported our activities in Northern Ireland so far during 2016.

With their support we have been able to support even more people throughout



Gail & Nick Rusk present cheque to Michelle McMaster

Northern Ireland and to grow and help develop our volunteer team with a view to reaching out more widely in the second half of 2016 and into 2017.

Funders include Big Lottery Awards for All NI, Ulster Garden Villages, Public Health Agency (PHA) and CLEAR Project, Belfast Cathedral Sitout (Black Santa) and Enkalon Foundation.

Growing & learning together

We appreciate the continued support of our local Health and Social Care Sensory Support Teams and of our range of Audiology Services.

Through our colleagues, we have taken part in a number of Hard of Hearing Clubs, Tinnitus Support Groups and Lipreading Groups, and supported patients at the regional NF2 clinic.

Hearing Link remains an active member of the NI Coalition on Deafness, working together to influence and improve access to public services provision for people with hearing loss.

As part of the Coalition, we took part in a Hustings Event prior to the May election and one of our volunteers asked about the level of communication support available for people with hearing loss.

Becoming a volunteer-led organisation

2016 is heralding some big changes for volunteering with Hearing Link.

Volunteers are integral to the work of our organisation, providing insight, understanding and peer-led support to meet the needs of people living with hearing loss.

Most of our volunteers live with the effects of hearing loss every day, directly or indirectly, and their unique perspectives are helping to shape the future of our organisation and the services we provide.

Our new Volunteering Strategy forms a key part of our wider 2016-2020 organisational strategy and has been strongly influenced by volunteer input.

The strategy adopts a much stronger focus on volunteers taking the lead and aims to provide a mutually satisfying

experience which encourages creativity and innovation.

Based in the local communities that we serve, volunteers are able to make sure we remain relevant and appropriate to the needs of those communities, ensuring we don't duplicate existing services while remaining open to new initiatives.

There is no doubt that through our volunteers, many more people with hearing loss, and their families and friends, will be supported in ways that help improve their confidence, skills and self-esteem.

However, there are equally important benefits to volunteers themselves, and through our new strategy we aim to support more volunteers so they can contribute in ways that suit them best and which promote their own personal growth and self-development.

“

As well as giving me a sense that I am putting something back into Hearing Link, volunteering as a facilitator helps me continue to improve my ability to handle my own hearing loss. It is a real win-win situation.

Lyndon,
England volunteer



”

UK Volunteer Working Group

To help deliver our ambitious strategy, we are focusing on building strong foundations to help support our emerging volunteering structures.

These will reflect local, regional, national and specialist interests, and will be supported by a new UK Volunteer Working Group.

This group is made up of volunteers representing each UK country, overseen by our Board of Trustees, and is taking on the challenge of guiding and helping to implement our volunteering strategy.

The first meeting of the UK Volunteer Working Group was held on 8th June.

We're delighted to reach this milestone in our organisation and believe the volunteers leading this group will result in even more people with hearing loss benefitting from our support.

We also believe it will result in volunteering with Hearing Link becoming an even more positive experience.

Through this group, we are growing our local and regional teams of volunteers and finding ways to make sure everyone feels well connected to each other, whether face-to-face or remotely as we find better ways to harness the power of digital technologies.

Join us!

Our volunteering team is growing throughout the UK and your skills and experience are needed!

We want to support more people in their own local areas; and to do this, we need people who can offer their knowledge and expertise of leadership, including, for example, skills related to mentoring, supervision, training, group facilitation and policy development.

We also need volunteers to support us within their communities by distributing literature, speaking to local groups and clubs, organising community fundraising events and through the delivery of our range of very practical and effective specialist programmes for people with hearing loss. If you would like to help us, please get in touch — details below.

To find out more about volunteering, email michelle.mcmaster@hearinglink.org

James wins the Heather Jackson Award

Congratulations to our Northern Ireland volunteer, James Newell, who has been named as the 2016 recipient of the Heather Jackson Award.

James was announced as the winner at the National Association of Deafened People's (NADP) AGM held at The Ear Foundation in Nottingham on June 12th.

The Heather Jackson Award is awarded annually to a deafened person who has made a significant contribution to the improvement of the welfare and opportunity of deafened people. It has been instituted in memory of NADP Chairperson, Heather Jackson, who passed away in 2007.

James has lived with hearing loss since he was four years old as a result of illness. Now a cochlear implant user, he plays a huge role in supporting deafened people across Northern Ireland.

He is passionate about supporting other people to learn better ways of living with their hearing loss and loves to see people 'come out of their shells and fulfil their potential'.



In his twenties, James started out working towards employment in the IT world, but quickly decided to use his life experiences to help others with hearing loss have a better future.

For the past 12 years, he has worked full-time as a Social Work Assistant for the Sensory Support Team in Belfast — a fantastic asset to the team.

“

I'm very pleased to have been acknowledged for doing something that I love.

*James Newell,
Heather Jackson Award winner 2016*

”

James was the very first volunteer to get involved with Hearing Link in Northern Ireland in 2013, after he found out about our charity at a talk given to his workplace.

He has been a tireless and enthusiastic volunteer for Hearing Link since then, playing a vital role in building our reputation and capacity across the country including helping to deliver our Self Management Programmes, Hear & Now events and speaking on behalf of Hearing Link at a NI Coalition on Deafness event in Stormont (Northern Ireland Parliament Buildings).

On top of all this, James is also a keen sports enthusiast, and takes an active lead in organising and supporting deafened people to become involved with a number of sporting interests, including those connected with football, bowling and badminton, to name just a few.

He has also helped organise numerous international trips for groups of deafened supporters who have travelled to see their teams play in several countries, and who have connected with local deaf groups wherever they have travelled so they could build the sense of international camaraderie between fans.

At home, James is partner to Paula who is profoundly Deaf, and has two young children (Amie and Duncan) who both have full hearing and speech, but who are equally comfortable using sign language with their mum and taking account of their dad's needs such as lipreading or reducing background noise.

James said: "Receiving the Heather Jackson Award has really taken me by surprise!

"I'm very pleased to have been acknowledged for doing something that I love — bringing laughter back into people's lives who have forgotten how to laugh due to their hearing loss.

"I really enjoy my role in Hearing Link as it allows me to give something back and to be a positive influence on the lives of so many."

Lorraine Gailey, Chief Executive of Hearing Link, added: "James gives to others freely and generously in all areas of his life. He's an incredibly positive role model for others, helping them to make changes that are lasting and beneficial.

"His ability to raise awareness and help integrate the worlds of hearing and deafened is inspiring and the energy he gives to that is relentless.

"James never asks for any thanks or reward for what he does, and in many instances he is unaware of the scale of the positive difference he has made on others.

"James is an inspiration to many and a worthy recipient of the Heather Jackson Award for 2016."

NEWSFLASH!

Hearing loss booklet

We've joined forces with BT to create a new booklet to support people with hearing loss. Called '**Communication Choices: your hearing, your life**', the guide aims to support people through their journey from diagnosis to where to get support. It also includes useful information about assistive communications equipment and services available including amplified phones, hearing loops and Next Generation Text provided by BT. Email helpdesk@hearinglink.org to request your free copy.

Lipreading tutor wanted

The Leslie Edwards Trust has an opportunity for anyone interested in lipreading to train as a tutor. The organisation, which supports lipreading classes in Leicestershire, has funding available to provide full training. Interested candidates should have some experience/knowledge of hearing loss. The successful candidate will deliver lipreading classes in the region upon completion of training. To find out more, visit <http://www.leslieedwardstrust.btck.co.uk/>

New Hearing Link website

We launched a new and improved website at www.hearinglink.org in April. The new-look platform is now mobile compatible including laptops, tablets and phones, as well as desktops. This means you can browse our website and keep up-to-date with our latest news from the comfort of your home or on the go. Over the coming weeks and months we will be adding new information and features. Please let us know what you think about our new site — email media@hearinglink.org with your comments/suggestions.

Lipreading Awareness Week 2016

Do you struggle to hear in restaurants? Even people with good hearing complain about the noise. Each year the Association of Teachers of Lipreading to Adults (ATLA) holds Lipreading Awareness Week (12th-16th September). This year, it has asked the restaurant trade to join them by choosing a day during the week to turn off their music, turn up the lights, and use tablecloths. ATLA hopes this will lead to some restaurants becoming hearing friendly. For more info visit www.atlalipreading.org.uk or email LAW@atalipreading.org.uk



Neuro Designed for a future of sounds

Oticon Medical's first cochlear implant system combines the best of hearing instrument and cochlear implant technologies.

Find out more at
www.oticonmedical.co.uk/Neuro



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sound matters

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Three cheers!



A big thanks must go to three companies for their support by choosing us as their Charity of the Year.

Aston Hearing Services (branches in Buckinghamshire and Oxfordshire), **Audify** (Exeter) and **The Tinnitus Clinic** (10 clinics nationwide) have all selected Hearing Link as their charity for 2016.

Staff from each company are organising raffles, evening events, open days and membership offers, with more planned. We will be sharing activities that you can attend at their premises through our social media channels.

Having raised over £1,000 already, this ongoing commitment helps us grow and develop as an organisation, and reaches more people who need us out in the community.

Inspirational fundraising

Fundraising this past year has been incredibly inspiring. Six runners showed their determination and nerve by taking part in full and half marathons since October.

Every step their worn feet have taken has been to raise valuable funds for our services. Together they have raised an amazing **£7,600** — and counting!

We would like to give a tremendous thank you to:

- Chris Cartwright (VLM 2016)
- Jimmy Turner (VLM 2016)
- Nigel Thorne (VLM 2016, Edinburgh Marathon 2016)
- Sioned Mair-Taylor (Manchester Great Run 2015, Royal Parks Half Marathon 2015, VLM 2016)
- Rob Chambers (Royal Parks Half Marathon 2015)
- Rosemary Clancy (Brighton Marathon 2015)

If you have been inspired by the stories you have read and want to raise funds for Hearing Link, there are a number of challenges still taking place this year which you can apply to be part of.

These include:

- Bournemouth Marathon and Half Marathon (2nd October)
- Royal Parks Half Marathon (9th October)

Find out more at: www.hearinglink.org/get-involved/fundraising-events.

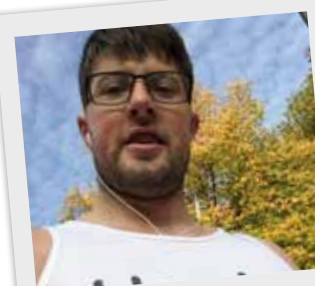
Alternatively, if you have already booked your place on a different challenge event and would like to raise funds for Hearing Link, email fundraising@hearinglink.org with your details.



Sioned Mair-Taylor



Chris Cartwright



Robert Chambers

Karen, our skydiving Queen!

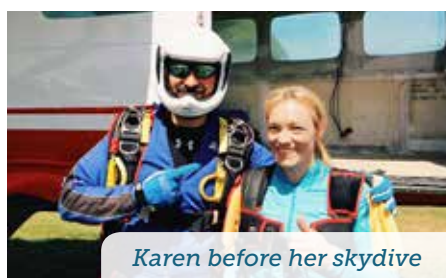
In May this year, our book-keeper Karen Read swapped her invoices for a parachute when she went above and beyond her professional duty to skydive for Hearing Link.

Karen, from Eastbourne, took the plunge of 10,000ft for her tandem skydive.

She said: "I'm not 100% sure why I wanted to do a skydive — I think I might have lost the plot!"

"I guess I just decided that now would be a good time to fulfil something I've wanted to do for ages .

"Hearing Link provides valuable support



Karen before her skydive

for people with hearing loss, I'm delighted the funds I raise will go towards their unique and life-changing support."

Karen's raised an amazing **£732.50!** Well done!

Can you help us transform lives?

If you have been moved by any of the stories in our magazine, please think about donating to Hearing Link through a single one-off or regular donation, payroll giving or a gift in your will. Your generosity will help us to support more people across the UK. Find out more at:

www.hearinglink.org/donate

Up for a challenge? Email fundraising@hearinglink.org to find the right one for you.



*The Hearing Link
Helpdesk was
extremely easy to
contact and gave
lots of essential
information
& support. ”*

Shona Hudson, Helpdesk Enquirer

We understand that hearing
loss affects far more than your
ability to hear.

Our **Helpdesk** can provide the
information that suits your
individual needs and those of
your family & friends.

Email, call or SMS today
with your questions:

Email: helpdesk@hearinglink.org

Tel: 0300 111 1113

SMS: 07526 123255

Hearing Link is a UK charity active in England, Scotland, Wales and Northern Ireland for people with hearing loss, their family and friends.

Royal Patron HRH The Princess Royal
Reg Charity No: 264 809 Scottish Charity No: SC037688

www.hearinglink.org

