

# EDNA

**Employee Disability and Neurodivergent Advice**

**Presented by:** Lisa Richardson & Alice Morris  
EDNA Disability and Accessibility Advisors

NHS Hampshire and Isle of Wight  
Health and Wellbeing Programme

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## What is EDNA?

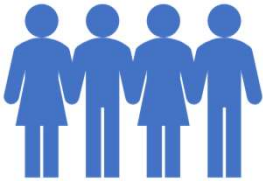
EDNA stands for Employee Disability and Neurodivergent Advice Service

A confidential information and advice service for NHS colleagues in Hampshire & Isle of Wight, who are living with a disability, long term condition and/or are neurodivergent

EDNA offers support and advice for workplace reasonable adjustments, information, signposting, advocacy, provision of manager training and more

The service is provided by a specialist team, who offer one-to-one advice and a safe space to talk, as well as help with areas such as: employment rights and HR advice




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## What is EDNA'S aim?


- Provide a *comprehensive* advice service
- Create a *healthier and comfortable* working environment
- Build a more *inclusive culture* within the workplace
- Empower colleagues with *timely* and *accessible* information

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## MEET THE TEAM


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**Lisa Richardson**  
**EDNA Disability & Accessibility Advisor**  
Lisa believes in a sense of belonging and acceptance and wants to share this journey with you, and make it be the best it can be so that we all feel a sense of achievement and as a whole being, where inclusivity is all.



**Alice Morris**  
**EDNA Disability & Accessibility Advisor**  
Alice believes that a sense of belonging ties diversity, equality, and inclusion together, ensuring that colleagues are respected, valued and understood whilst being their authentic self.



**Jacqueline Holt**  
**EDNA Administrator**  
Jacquie believes for us to put "patients first" we must firstly put our staff first. If we look after our staff we will have less sickness, reduced turnover of staff, therefore creating a more inclusive workforce.

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## Our aim for today's session...

- ✓ Raise awareness and understanding on some of the sensory impairments
- ✓ Discuss what support is available
- ✓ How to access support
- ✓ Introduce our guest speaker and a lens through a disability


Be ready for when we say **Quiz time**

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Let's learn about what is a sensory impairment?



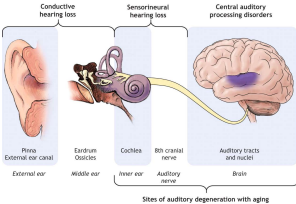
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A sensory impairment is when one of the senses – sight, hearing, smell, touch, taste or spatial awareness – is not working as it should.

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So, lets begin with hearing



The diagram illustrates the path of sound from the external ear to the brain. It is divided into three sections: Conductive hearing loss (Pinna, External ear canal, Eardrum/Ossicles), Sensorineural hearing loss (Cochlea, 8th cranial nerve), and Central auditory processing disorders (Auditory tracts and nuclei, Brain). A bracket at the bottom indicates 'Sites of auditory degeneration with aging' covering the cochlea, 8th cranial nerve, and brain.

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**What is meant by hearing impairment?**  
Hearing impairment is a medical term adopted by many professionals. However, some people who are deaf with a capital D (Deaf) may find this offensive and prefer an alternative term.

**What is meant by hearing loss?**  
A person who is not able to hear as well as someone with normal hearing – 'hard of hearing' refers to people with hearing loss ranging from mild to severe. People who are hard of hearing usually communicate through spoken language and might benefit from hearing aids, cochlear implants, and other assistive devices as well as captioning.

**What are the characteristics of hearing disabilities?**  
Hearing specialists classifies hearing loss using four different levels:

- Mild
- Moderate
- Severe
- Profound

The terms 'mild' and 'moderate' can sometimes be misleading, as they do not reflect the impact that these levels of hearing loss will have on the individual (RNID, 2022).



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**What term is used to refer to a deaf person?**


Deafness is a spectrum that ranges from mild hearing impairment through to total hearing loss.  
We recommend that you ask the deaf person how they would like to be referred to. Below are some terms that are most often used:

- Deafblind
- Hard of Hearing
- Hearing Impaired
- Hearing Aid User
- Hearing loss
- Deaf

**Hearing loss** refers to someone who may not use British sign language also known as BSL but uses hearing aids to support hearing.


**'deaf' person** might use BSL and mainly identifies with the hearing community and may socialise with the deaf community.

**'Deaf' person** identifies as a Deaf person using a capital letter 'D' which indicates that they socialise with the Deaf community, they feel that they are part of a community. This group of people use BSL as their first or preferred language.



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We would now like to present some short videos produced by:  
Annie Harris, Portsmouth Hospitals University NHS Trust




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[My Background As A Deaf Person – YouTube](#)  
[My Experiences As A Deaf Patient - YouTube](#)  
[Deaf Inclusion – YouTube](#)  
[Deaf Culture – YouTube](#)  
[Deaf Communication Tips - YouTube](#)

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**Quiz time**

**What might be common signs of hearing loss?**  
 Please enter your thoughts into the chat field



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**Common signs of hearing loss**

Hearing loss often happens gradually, so you might not notice it at first. But here are some common signs to look out for:

- ✓ Turning the TV up louder than your family wants it
- ✓ Finding it difficult to follow conversations in pubs and restaurants
- ✓ Struggling to hear on the phone
- ✓ Often asking people to repeat what they have said
- ✓ Having a friend or relative complain that you don't listen to them
- ✓ Thinking that other people are mumbling

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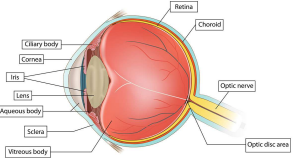
**We would now like to introduce you to our guest speaker:**  
 Sam Burgess, Southern Health NHS Trust



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Now let's talk about **visual**


**Anatomy of the Human Eye**



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**What is meant by visual impairment?**  
 Visual impairment is an umbrella term used to describe many kinds of visual loss, whether a person can see or not, it can be used to describe people who experience a decrease in the ability to see to a certain degree (have a minimal vision or a degree of usable vision) and those that are unable to see at all.


**What is blindness?**  
 The word "blindness" is commonly used to describe total, or near-total sight loss.



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**Globally, the leading causes of vision impairment are:**

- Age-related macular degeneration
- Cataract
- Diabetic retinopathy
- Glaucoma
- Uncorrected refractive errors



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Yes its that time again.... **Quiz time**


**Let's see if you know some of the different types of vision loss?**

For the next three slides on each slide please add your thoughts in the chat field



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Slide 1



Can you guess?

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Slide 2



Don't forget to add your thoughts into the chat field if you think you know....

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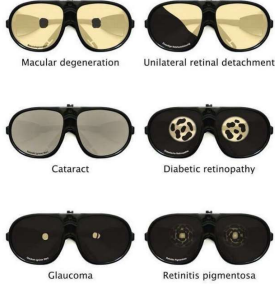
Slide 3



Have you aced it? Or, would you like to know?

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Answers



Macular degeneration    Unilateral retinal detachment

Cataract    Diabetic retinopathy

Glaucoma    Retinitis pigmentosa

Did you guess correctly?

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**We would now like to show you a short video produced by:**  
Amy Long, University Hospital Southampton

[Amy's story, through the lens of disability - YouTube](#)

**NHS**  
University Hospital Southampton  
NHS Foundation Trust

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**Quiz time**

**What are some of the common signs of a visual impairment?**

Please enter your thoughts in the chat field



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- Blurred vision
- Pain in the eye(s) with or without discharge
- Sensitivity to light
- Double vision
- Flashes of light in your vision
- Disturbances in your vision
- New floating bits in your vision



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**Lets talk about a couple of case studies** and what some adjustments might be



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#### **CASE STUDY 1: Let's talk about Ava**

Ava is deafblind. She wears cochlear implants and uses special software to be able to read computer screens. Since school she has had an interest in working in IT and read a Masters in IT. She recently found employment, after being unemployed for several years. However, while unemployed, she took part in volunteer work and made sure she kept her skills up-to-date on training courses.

Ava is well supported in her current role – her manager was proactive with understanding her support needs and arranged a meeting one month prior to her starting the role to discuss what reasonable adjustments would be needed. Allowing time for adjustments to be made so that Ava was able to start her role from the beginning. Her manager also scheduled regular meetings to discuss the adjustments, her manager is aware that her needs could change depending on the job and her disability.

Ava's team are aware of her communication needs, so that during meetings, colleagues will take notes for her in meetings or will arrange interpreters for meetings which require networking.

Ava also uses Access to Work, which includes taxi travel to and from her workplace, and has helped with adjustments needed such as a large display screen monitor with high resolution, and specialist software for visual impairments.

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#### **CASE STUDY 2: Let's talk about Tony**

Tony is a senior manager at a large company. He is deafblind and uses lip reading to understand what people are saying. At work he requires certain adjustments, such as specialist software, and needs to sit in a certain position during meetings in order to lipread.

He has been able to engage with his employer and get them into a mindset to think of what he can do, as opposed to what he cannot do, and believes it is very important that everyone adopts this attitude.

Whilst it is good to be aspirational, it is about managing expectations and finding a job where you can maximise your talents. "The key to his success has been through being open and honest about what he can do and what he can't do.

He is not shy to go into a meeting room and rearrange where everyone sits for him to get the maximum benefit of communication. We all have different needs and these just happen to be his. It is about working with your employer and changing the way of thinking of reasonable adjustments into a return on investments.


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**Access to Work**  
Support for reasonable adjustments in the workplace, if you have a disability or health condition



**Access to Work**  
Making work possible

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Lets watch a short video to learn more about Access to Work

[Your Guide to Access to Work - Bing video](#)

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"Many reasonable adjustments are inexpensive and relatively straightforward to make"

(Sense,2023)

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Some examples of what reasonable adjustments could look like



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**FACTS**

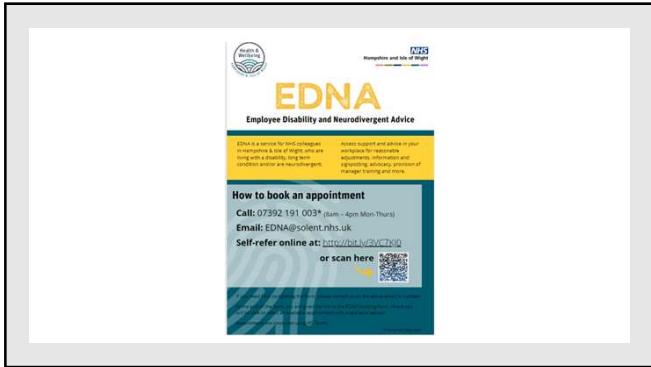
- In the UK one in 30 people have sight loss
- There are more than 11 million people in the UK, or one in six of the population, with some form of hearing loss. More than 900,000 are severely or profoundly deaf
- In the UK, more than 2 million people are living with sight loss. Of these, around 340,000 are registered as blind or partially sighted
- By 2050, the number of people with sight loss is set to double due to increases in risk factors such as obesity, diabetes and age

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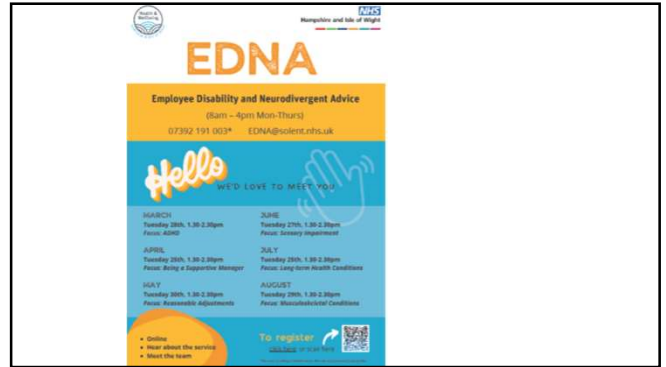


If someone does not get the reasonable adjustments they need at work they could make a disability discrimination claim to an employment tribunal!

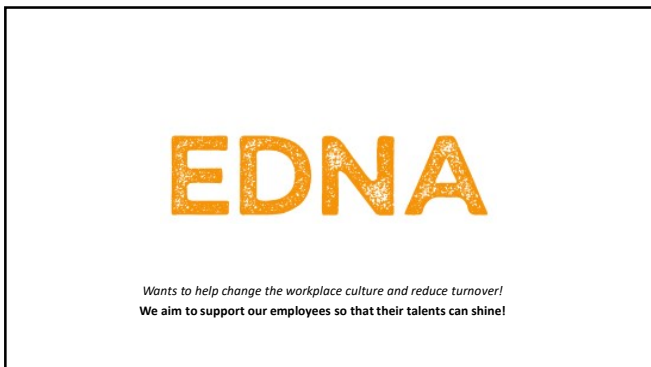
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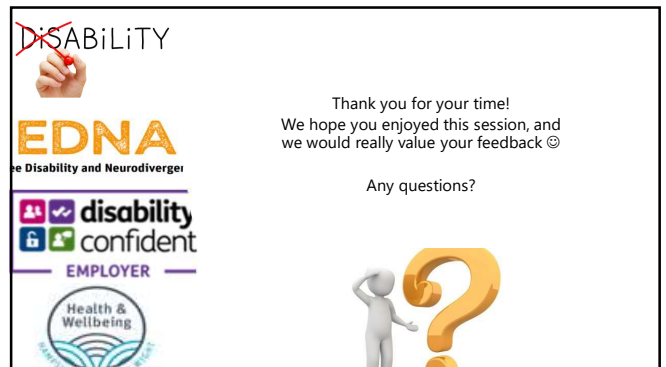
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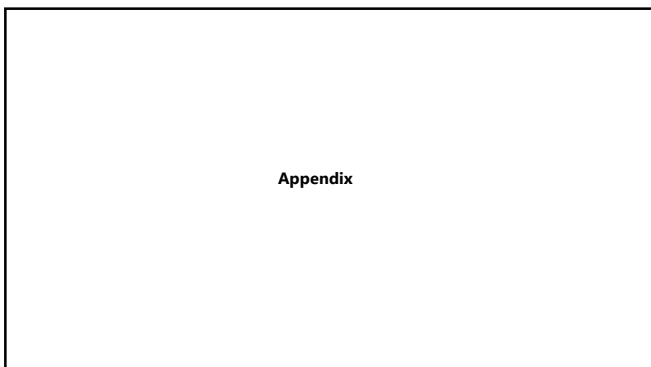
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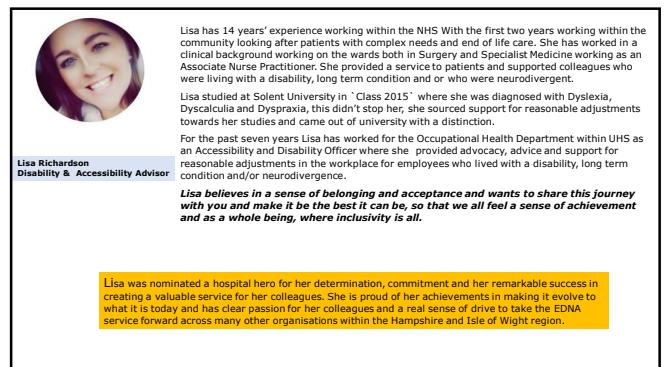
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**Alice Morris**  
Disability & Accessibility Advisor

Alice has worked within the NHS for four years; within the first two years Alice worked for the Children & Families Service as a Speech & Language Therapy Assistant where she worked within various settings; organising and delivering therapy activities. Alice has supported individuals who have a disability and those who are on the autistic spectrum.

For the past two years Alice has been working as part of the Operational Management Team in Solent NHS Trust's Vaccination and Health Inequalities Service. Alice was involved in the development and coordination of vaccination centres across Hampshire & IOW and within a variety of community settings.

Prior to Alice's time working for the NHS, she has enjoyed working in a range of different roles supporting people with social and physical learning disabilities. This led Alice to pursue a degree in Special Educational Needs & Disabilities which has given her a broader understanding of how to better support individuals with a disability and/or long-term condition.

Alice believes that a sense of belonging ties diversity, equality, and inclusion together. Ensuring that colleagues are respected, valued, and understood whilst being their authentic self.


*"Alice is excited and passionate about the service and looks forward to offering support and advice to NHS colleagues and helping them flourish in the workplace."*

Alice was diagnosed with Dyslexia, Dyspraxia & Dyscalculia during her time at university in 2015 where she sourced support for reasonable adjustments towards her studies and has continued to use these in everyday life.

Alice talks openly about her disability as it is an important part of who she is.

*"Good friends will stop seeing condition or impairment as a barrier but just an aspect of your life. It won't be the only thing they know about you."*

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**Jacqueline Holt**  
EDNA Administrator

Jacquie has many years experience of working in Childcare. Jacquie has 5 children, 1 who became deaf following meningitis at 16 weeks, 1 who had severe asthma and eczema and then at 16 her eldest son unfortunately took his own life. This has led to Jacquie having multiple health issues, including depression and anxiety, following his death.

Jacquie had a very simple accident whilst away on a Scout camp, which left Jacquie with chronic pain and has undergone many spinal operations. She is now registered disabled and has mobility issues.

Jacquie vowed never to let any of her disabilities stop her and worked hard to stay in work and learnt to walk again. Her goals are to stay at work even if its 1 day a week, and has the support and assistance of her main carer (her husband) and her therapy Maine Coon Cat.

Since her accident Jacquie has achieved several NQ3 qualifications and says her proudest moment was when she achieved her HNC in business management – through distance learning whilst also holding down a full-time job and her busy family life.

**Jacquie believes for us to put "patients first", we must firstly put our staff first.**  
**She believes, if we look after our staff, we will have less sickness, reduced turnover of staff, therefore creating a more inclusive workforce.**

**We want our staff to be able to do their roles alongside their colleagues along a level playing field.**

Jacquie worked closely with the Equality, Diversity and Inclusion team to set up a new staff network to support employees with a disability and/or long term condition.

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**Why we started the service, what impact do we want, how passionate are we?**

- ❖ Keep staff supported
- ❖ Improve staff retention, and morale
- ❖ Benefit our employees' Health and Wellbeing
- ❖ Focus on employee's experience within the workplace
- ❖ Solve problems before they impact our colleagues and the service

**Employees who experience burn out are less productive, incur more health costs and are at greater risk of serious illness!**


Unless employees feel their best both physically and emotionally, they can never be fully engaged with their organisation!

**EDNA is about employee engagement, with its overall aim to improve the wellbeing of the workforce.**

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What can we do as a workforce on a personal level?

- ✓ Get to know each other
- ✓ Use person centered language
- ✓ Question your own thoughts and attitudes towards individuals who have a disability
- ✓ Say or do something if you see discrimination
- ✓ Support inclusion



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*"Organisations must consider the broader picture; inclusion is more than simply 'including' diversity – it is about individual experience and work, and creating a positive environment in which everyone can influence, share knowledge and have their perspectives valued"*

(The Chartered Institute of Personnel and Development, December 2022)

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**EDNA**

- ✓ Listens to our employees, which can make the organisation a great place to work
- ✓ Can help our employees feel valued
- ✓ Focuses on creating an inclusive environment
- ✓ We help communicate that the organisation is a good employer

**The stronger we are together the more likely we are to attract and retain!**

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We have asked our people, and their managers what matters most

They said...

- ❖ Access the right support
- ❖ Felt unable to ask for help
- ❖ Worried that they might be treated differently
- ❖ Afraid to speak up, or disclose their disability and/or condition

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#### Facts

- ✓ Employee's or employers do not need to struggle
- ✓ Reasonable adjustments can enable a person to bring their best self to work
- ✓ With reasonable adjustments in place, individuals are more likely to stay working for their employer
- ✓ With the right support and tools employees will be more productive
- ✓ We can work together to achieve the best for each other
- ✓ We can guide you in the right direction
- ✓ We can help make the workplace an inclusive and supportive environment
- ✓ Where everyone matters and every voice counts



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**Access to Work can usually provide a grant to pay for the cost of the support, for example it can provide funds towards:**

- Special aids and equipment
- Adaptations to equipment
- Travel to and from work
- Communication support at interview
- Support workers
- Mental Health support



You are considered disabled if you have a physical or mental impairment which has a substantial and long-term adverse effect - beyond 12 months - on your ability to carry out day-to-day activities (Equality Act, 2010)

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**Many reasonable adjustments involve little or no cost and could include:**

- Making changes to an individual's working pattern
- Providing training or mentoring
- Making alterations to the workplace premises
- Ensuring that information is provided in accessible formats
- Modifying or acquiring equipment and/or software
- Allowing extra time during exams



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Good afternoon everybody, my name is Sam Burgess and I am the library service manager for Hampshire Healthcare Library Service covering Southern Health and Hampshire Hospitals.

I must start by saying that I cannot speak for all deaf people as our experiences and requirements are very personal and will differ from one person to the next. So please do not assume that my experience will be the same for the next deaf person you meet – the best thing you can do is to discuss with that person that their needs are and how they are best supported.

So on to my story, I have been deaf since birth as my Mum had rubella (what was known as German measles) while she was pregnant with me. I have been confirmed as being profoundly deaf although my Mum had to battle the GP who dismissed her several times saying that I just had a cold. I have since had hearing aids since I was about a year old and have now had a cochlear implant. Going back to the point about deaf people being different – some might assume that because I have a cochlear implant that I do not use sign language. That might be true in my case (my skills are very rusty because I do not practice!) but other people with cochlear implants may prefer to use their BSL as it is their first language.

The other thing that tends to be assumed is that cochlear implants magically restores all hearing – again, different people have different experiences. Those people who have been recently deafened will get far more out of an implant than I ever will. In my case, I have been deaf for over 40 years (keeping the exact years to myself!) and so my brain no longer recognises what a certain sound should sound like. That said, the brain is incredibly plastic and quite willing to learn what these new electronic sounds mean.

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So as I was making a cake the other day and I was pouring sugar into the bowl I was delighted to be reminded that I could now hear those grains of sugar hitting the bowl. I never thought that a ticking clock could be so irritating – if there are other sounds in the room I cannot hear the clock but in the quietness I do and I have yet to learn how to cut that sound out.

The frustration for me is that I still have to lipread – of course context matters and I am just as likely to respond to a sentence given in a quiet room without looking at the person if I have a rough idea of what they are going to say and the sentence fits what my brain expects to hear. But by and large I still need to lip read, however when I take my ears out (at night or I am having a lazy Saturday) I find that my ability to lipread without sound is nowhere near as good as it used to be and I used to pride myself on my lipreading skills so this does show that I am relying more and more on what my implanted ear is giving me.

Interestingly, when I had hearing aids in both ears, I used to consider my right ear the better of the two, but now when the cochlear implant battery goes flat and I am left with my hearing aided ear, I am appalled at just how little I can hear! For your information the cochlear implant processor relies on rechargeable batteries and the hearing aid has disposable batteries – something I have to think about nightly when plugging in the batteries or when I am away for a weeks holiday and I have to think about all the equipment and batteries I need to bring to ensure that I am fully functioning!

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I have many key moments in my life, but here are a few that are specifically around being deaf and how I have been supported or not as the case may be. I have been very fortunate to have been largely very well supported indeed across my career as an NHS librarian.

So, I started as a senior library assistant straight out of university and I have now reached the giddy heights of a library service manager (when I look back, I always thought that senior managers were scary people, but now I realise that they are the same people they have always been just with more experience and knowledge!

What I do remember though, is that just before starting my second job I had to go through occupational health clearance like everybody else does. However, occupational health didn't quite know what to do with me (this was about 23 years ago) and there were a few days when I was quite genuinely concerned that I would not have a job to go to!

In contrast, I now have a team that wait for me to turn Teams captions on (why can't they be on by default at all times!), or will save me a space the front of training sessions, and readily accept that I do not use the telephone.

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A more recent moment is one that I simply didn't know how to respond to – a colleague actually said "it would be so much easier if you could use the phone". Yes, I admit that is quite true, but the fact of the matter is that I cannot use the phone and to be made to feel like a nuisance because I can't use the phone is really quite painful. And when I say more recent, this was in the last 5 years so discrimination has not gone away and we still need to fight our battles. I was so struck by the comment that I didn't know how to respond and to this day I am still not sure how I could have responded.

A moment that made me reflect though is one that still makes me smile. You know how when you're writing something down on a piece of paper you are looking down in order to write, but at the same time you might be asking someone a question – well, I had someone wanting to join the library and so I was writing and asking them questions, when all of a sudden a hand waved in front of my face and so I looked up to see the student physiotherapist say "I am deaf, please can you face me while talking so that I can lipread". Put simply, I had done what everyone else does and had assumed that the person in front of me did not have a hearing loss (or indeed any other disability).

I am glad to say that we both laughed when we realised and we found that we had friends in common. But, the point I am making is that if I can't recognise that someone is deaf and needs better communication then don't be too hard on yourself if you make the same mistake, just adapt and try again!

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Even in my personal life I have had a few discriminatory moments, one that still makes me roll my eyes is that I emailed an audiology department to ask for an appointment as my hearing aid was not working. I then had a missed phone call from an unknown number, when I looked up that number I saw that it was the local audiology department. A few minutes later I had an email from them asking to supply a phone number in order for them to call to arrange an appointment. Two things – firstly I emailed them so I expect an email back, secondly, my hearing aid does not work so even if I could use the telephone I am even less likely to be able to do without my hearing aids. This was an audiology department – I expected better then and still do expect better now. I have been deaf for more years than I like to think, and while I went through the usual teenage agonies of wanting to be "normal" and covering up my hearing aids, I still find that even now I need to get out of my own way. For instance, it took me a long time to apply for Access to Work support because there was and still is a stigma around seeking more support. I did eventually get three year funding to Access to Work to support my need for captions during online training – then COVID happened and suddenly Zoom and Teams were offering automatic captions. They are not perfect but they give me more than enough to be able to keep up with the conversation that is happening in front of me. Even now I still find it hard to hear in very large groups – when I attend large group sessions like a recent away day I do state that I am deaf but when the conversation gets fast and furious or when I can't see the person at the other end of the room because there are other people in the way, then I have to make a judgment call as to whether this is important enough for me to say something.

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It's definitely a case of picking my battles, but I still wonder if I should have said something or not because I deserve to hear it all just as much as my colleagues would but the constant irritation of having to do so is wearying and puts me in the spotlight in a way that I would rather not being the introvert that I am!

To finish, being deaf is merely a part of me, I am not defined by the fact that I am deaf whereas it is probable (I don't know) that someone like Rose Ayling-Ellis would see her deafness as being a much larger facet of her being than I do. Which reflects that fact that we are all different, it is impossible to label people with a disability (any disability, not just deafness) and expect that we all have the same abilities, needs, and desires. So I leave you with a comment that a friend shared with me – "never think you know someone else's story. Always communicate with the individual in front of you and don't assume that you know what they need."

Thankyou, if you have any questions or would like to know more about my personal story or how cochlear implants work please do not hesitate to contact me via email: [samantha.burgess@southernhealth.nhs.uk](mailto:samantha.burgess@southernhealth.nhs.uk)

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