

Wales

Why urgent action is needed on deafness, tinnitus and hearing loss across Wales

Hearing Matters



**ACTION ON
HEARING
LOSS**

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A national charity since 1911





575,500 people have hearing loss in Wales

That's more than the
populations of Cardiff
and Swansea combined

Foreword



575,500 people in Wales have hearing loss – **that's more than the populations of Cardiff and Swansea combined.**

In Wales some progress is being made to make sure these people can remove the barriers in their way – and take control of their lives. For example, in 2013 Wales introduced the All Wales Standards for Communication and Information for People with Sensory Loss. This meant that Wales became the first country in the UK to outline clearly how NHS services should provide information in accessible formats – and communication support – for people with sensory loss.

Yet these standards still aren't having the intended impact. People tell us they are still leaving hospital unsure of how much medication they are meant to take or when their follow-up appointment is. It's a similar picture for people living with deafness or hearing loss who are trying to find work, or stay in their job. Our research shows that too many people in Wales are being discriminated against when looking for work.

We also need the Welsh Government and Local Health Boards to make sure people get the support they need, in their communities, through our volunteer-led clinics. Should these clinics close, as planned, in 2016, 6,000 people will be at risk of mental health problems and isolation. And, for people with tinnitus, there is still no set path for getting treatment. This needs to change, if people with tinnitus are to get the treatment they need.

These are just some of the issues facing people confronting deafness, tinnitus and hearing loss in Wales. We want to help people live the life they choose, by removing the barriers in their way. We're counting on your support.

Richard Williams, Director, Action on Hearing Loss Cymru

Agenda for change

What action needs to be taken...

Support and care

Public health

- The Welsh Government should make tackling the growing prevalence and impact of hearing loss a national priority.
- The UK's National Screening Committee should introduce hearing screening for all people aged over 65, in Wales.

Hearing services

- The Welsh Government should consistently monitor performance against quality standards and publish the results.
- Local Health Boards (LHBs) must commission and properly fund high-quality hearing services and make sure all the people who could benefit from hearing aids continue to receive them free of charge on the NHS.
- GPs and audiologists should improve the quality of their information and deliver ongoing support, which meets the needs of people with hearing loss.
- The Welsh Government and LHBs should work in partnership with voluntary-sector service providers. They should continue to fund the essential Hear to Help hearing clinics and other community-based, NHS aftercare audiology services across Wales.

Tinnitus

- LHBs, GPs and Social Services must deliver consistent, high-quality support services for people suffering with tinnitus.

Local Health Boards must make sure everyone who could benefit from hearing aids continues to receive them free of charge on the NHS

Equipment and support

- The Welsh Government should enforce requirements, under the new legislation, to provide equipment to and support for people with hearing loss.
- The Welsh Government should ensure lipreading classes are available for all those who could benefit.

Technology and treatments

- The Higher Education Funding Council for Wales should increase the Charity Support Fund in line with increasing spending by research charities.
- The Welsh Government should build capacity around hearing research, making it a strategic priority to establish Wales as an international leader in this area.

Equality

Access to health

- LHBs in Wales need to set out a timetable and meet a deadline for the full implementation of the All Wales Standards for Accessible Communication and Information for People with Sensory Loss, across all services.
- LHBs in Wales must provide mandatory induction training on sensory loss to all staff at every level, including senior staff.
- GPs and hospitals must make sure communication needs are identified, recorded and met for all patients, including updating the records of existing patients.
- LHBs should raise awareness of the standards amongst people with sensory loss and make sure there are robust procedures for reporting concerns and complaints when communication needs are not met.

Social care

- The Welsh Government should work with third sector partners, to ensure there is an appropriate level of support available across Wales for deaf people with additional needs.
- Local authorities should consider people's communication needs when allocating funds for personal budgets and make sure social workers are appropriately skilled to carry out assessments for people who are deaf.

Housing

- All social housing landlords in Wales should deliver support in line with the guidelines in our best practice document, including training all staff in deaf awareness and communications tips.
- The Welsh Government needs to monitor the performance of housing providers, to make sure they are following this guidance and meeting their duties.

Employment

- The Welsh Government must work with us, and partners such as the Department for Work and Pensions, to ensure that people with hearing loss have the same access and opportunities to work as everyone else.
- Employers should become familiar with the information and resources available to people with hearing loss, so they can be proactive in properly supporting employees who tell them that they have hearing loss.

Access to television and video on demand

- Broadcasters in Wales need to make sure that subtitles are available to both Welsh and English-speaking people who are deaf or have hearing loss.

Support and care

Public health

GPs fail to refer

45%

of those reporting hearing loss to NHS hearing services

575,500 people in Wales have hearing loss¹, and this number is set to grow as the population ages. It is estimated that 71.1% of over-70s have some form of hearing loss (Davis, 1995). About one in 10 people in Wales are affected by tinnitus (Davis, 1989).

If untreated, hearing loss affects the ability of people to communicate with others and can lead to social isolation (Gopinath et al, 2012; Pronk et al, 2011) and depression (Saito et al, 2010). There is also strong evidence of a link between hearing loss and dementia (Lin et al, 2011). Evidence suggests that the timely provision of hearing aids can reduce these risks and improve quality of life (Mulrow et al, 1990; Deal et al, 2015), but people wait on average 10 years before seeking help and GPs fail to refer up to 45% of people reporting hearing loss to NHS hearing services (Davis et al, 2007).

What action needs to be taken...

- The Welsh Government should make tackling the growing prevalence and impact of hearing loss a national priority.
- The UK's National Screening Committee should introduce hearing screening for all people aged over 65, in Wales.

¹ The estimates of prevalence of hearing loss in this section are based on the most robust and best available data for prevalence at each age group (Davis, 1995), updated with population estimates for 2014 (ONS, 2015), and rounded to the nearest 500.

Hearing services

Quality standards for adult audiology services were introduced in Wales in 2009, but more needs to be done to make sure these standards are delivered for patients.

It is important that audiology services are provided with the necessary resources to enable them to deliver services that the public expect under the quality standards – and their progress must be monitored and reported on.

Our *Under Pressure* research (Lowe, 2015) shows patients in Wales are facing increased waiting times for audiology services. This is because of increasing demand and a shortage of staff. Two Local Health Boards (LHBs), Abertawe Bro Morgannwg and Hywel Dda, have restrictions on bilateral hearing aids. This means that, contrary to clinical guidelines, patients in these areas with hearing loss in both ears will not always receive two hearing aids.

Good aftercare is also essential to enable people to adjust and get the full benefit from their hearing aids. After being fitted with hearing aids, two-thirds of people (66%) have trouble using them and need further support (RNID Cymru, 2009). Action on Hearing Loss runs free hearing aid clinics across Wales that provide information, emotional support and practical guidance for people with hearing loss, and their families. After visiting a Hear to Help clinic, only 29% of people found it difficult to manage their hearing aids (Action on Hearing Loss Cymru, 2014).

Funding for the Welsh Hear to Help service ends in 2016 and these services will have to close, leaving more than 6,000 people at risk of loneliness and communication difficulties, isolation and mental health problems. It will also put more pressure on the NHS – 84% of people supported by the service said they would have contacted audiology if Hear to Help were not available (Action on Hearing Loss Cymru, 2014).

Our Hear to
Help service
costs just
£25
per patient.
Closing it will
leave more than
6,000 people
at risk

The service costs just £150,000 to run each year, across the whole of Wales; that's less than £21,500 per health board, or £25 per patient.

What action needs to be taken...

- The Welsh Government should consistently monitor performance against quality standards and publish the results.
- Local Health Boards (LHBs) must commission and properly fund high-quality hearing services and make sure all the people who could benefit from hearing aids continue to receive them free of charge on the NHS.
- GPs and audiologists should improve the quality of their information and deliver ongoing support that meets the needs of people with hearing loss.
- The Welsh Government and LHBs should work in partnership with voluntary-sector service providers. They should continue to fund the essential Hear to Help hearing clinics and other community-based, NHS audiology aftercare services across Wales.

Tinnitus

Around one in 10 people in the UK are affected by tinnitus (Davis, 1989). Tinnitus is a ringing or buzzing sound in the ear or head that cannot be attributed to an external source. Most cases are related to ageing, hearing loss or noise exposure. It can also be a side effect of ear or head injuries, ear disease or infections and can be triggered or exacerbated by emotional trauma, illness or stress. Evidence suggests that tinnitus is linked to depression, which can worsen the perception of the condition (Dobie, 2003).

There is no clear path for people with tinnitus to follow to get help. GPs are not always equipped with the appropriate knowledge and information to help, and services vary across Wales.

Our research (Action on Hearing Loss, 2015) found only three LHBs (Betsi Cadwaladr, Cardiff and Vale, and Aneurin Bevan) offer access to cognitive behavioural therapy (CBT), which is one of the most effective tinnitus treatments available and recommended by the Department of Health.

This research also found that two LHBs (Betsi Cadwaladr and Hywel Dda) have recently reduced their tinnitus services.

What action needs to be taken...

- LHBs, GPs and social services must deliver consistent, high-quality support services for people suffering with tinnitus.

After a particularly busy month at work, I developed loud ringing in my ears. I knew I was under a lot of stress, and hadn't been sleeping well, but I was sure that, after an early night, the ringing would be gone. It didn't go away – and it never has.

Terrified I was having a nervous breakdown, I went to see my GP. Fortunately, he understood tinnitus and referred me to the audiology department for further tests. The audiologist diagnosed a mild hearing loss, which was exacerbating the tinnitus. She was frank: "There is no cure for tinnitus. You'll have to find a way of living with it".

My GP referred me for cognitive behavioural therapy, which was tremendous, and helped me to learn new ways to control my anxiety and panic attacks. Everybody's tinnitus is different, so everyone's way of coping will be different too. For me, it's a mixture of medication, working less, regular exercise and noises that distract from the tinnitus.

Five years on, the noises have never stopped. You never get used to it or stop wishing for silence. With determination you can live well with tinnitus but it takes a lot of strength and I know for some it has drastically reduced their quality of life and each day is a struggle.

Bev Frowen, 56, Rhondda Cynon Taf



Equipment and support

Under the Social Services and Wellbeing Act (Wales) 2014, local authorities have a duty to provide a range of support services and equipment for people with hearing loss. What is available varies, but it can include equipment for the home, support groups, counselling, advice on finances and benefits, British Sign Language (BSL) interpretation, and advocacy services.

Our research report *Life Support* (Calton, 2012) found that all local authorities that responded to our survey provided social work and social support, equipment, occupational therapy and advice, but seven (12%) did not provide crucial interpretive support.

We want the Welsh Government to commit to providing high-quality rehabilitation services for people with hearing loss. For example, lipreading classes are vital – they teach people to recognise lip shapes and patterns, and help them make sense of conversations.

The Welsh Government has funded the training of 12 new lipreading tutors to increase the number of lipreading classes, but local authorities and health boards are not commissioning their services.

What action needs to be taken...

- The Welsh Government should enforce requirements, under the new legislation, to provide equipment and support for people with hearing loss.
- The Welsh Government should ensure lipreading classes are available for all those who would benefit.

Technology and treatments

Evidence shows that, per head of population, Wales attracts a smaller amount of research funding from charities and research councils than Scotland or England.

Researchers at Cardiff University are investigating speech perception at events with high levels of background noise, such as parties and other social gatherings. We hope this research will lead to better acoustics in rooms and improvements in the design of hearing aids and cochlear implants.

This expertise should be used to attract further investment – and establish Wales as an international leader in background noise research.

What action needs to be taken...

- The Higher Education Funding Council for Wales should increase the Charity Support Fund in line with increasing spending by research charities.
- The Welsh Government should build capacity around hearing research, making it a strategic priority to establish Wales as an international leader in this area.

Equality

Access to health

9 out of 10 patients haven't seen any improvements in the way hospitals share and communicate information

Wales was the first country in the UK to introduce standards for accessible information (NHS Wales, 2013).

The All Wales Standards for Accessible Communication and Information for People with Sensory Loss provide clear guidance on what GPs and hospitals should do to make their services more accessible for people with hearing loss and sight loss. It aims to make sure people with sensory loss can understand the health information they are given; and have access to a qualified BSL interpreter, or other forms of communication support, during NHS appointments.

Disappointingly, patients with sensory loss tell us that they are not seeing the increased accessibility they were promised (Action on Hearing Loss et al, 2014). Many people with hearing loss are still facing needless barriers in hospitals and doctors' surgeries.

Patient A's story

I had surgery. I asked for [a British Sign Language] interpreter; the staff did not know how to book one... Eventually [they] said a nurse would be present for my admission and surgery. When I was admitted and had surgery, the nurse wasn't there. I signed the consent forms for surgery not understanding the medical jargon on them. I could not understand the surgeons before and after surgery.

Approximately nine out of 10 (91%) patients were not aware of any improvements in the way healthcare services communicate and share information since the standard was introduced.

Only one in five (20%) patients said they were asked about their communication and information needs, and approximately half (58%) did not know how to report a concern or complaint.

What action needs to be taken...

- LHBs in Wales need to set out a timetable and meet a deadline for the full implementation of the All Wales Standards for Accessible Communication and Information for People with Sensory Loss, across all services.
- LHBs in Wales must provide mandatory induction training on sensory loss to all staff at every level, including senior staff.
- GPs and hospitals must make sure communication needs are identified, recorded and met for all patients, including updating the records of existing patients.
- LHBs should raise awareness of the standards amongst people with sensory loss and make sure there are robust procedures for reporting concerns and complaints when communication needs are not met.

3 out of 4

local authorities in Wales didn't provide a textphone number or special telephone service

Social care

Social care services are provided for many older people, but also for working age adults and children with hearing loss, and other forms of sensory loss, learning disabilities, mental health problems and long-term conditions. In our *Life Support* (Calton, 2012) research we found that communication needs are not taken into account in the systems used to determine an individual's social care budget in a third of local authorities (33%) in Wales. We also found that three-quarters (75%) of local authorities in Wales did not provide a textphone number or special telephone service for people with hearing loss.

We welcome duties under the Social Service and Wellbeing (Wales) Act 2014 for local authorities to promote the wellbeing of social care users, assess needs and involve people in discussions about their care. It is vital that social care staff have the right knowledge and communication skills to meet the needs of people with hearing loss. Local authorities also have a duty to provide advocacy support where needed, but our *Life Support* research found a quarter did not provide advocacy support for people with hearing loss. Advocacy services must be fully accessible to people who are deaf. We want the Welsh Government to commit to work with third-sector partners, to develop advocacy services for people who are deaf.

What action needs to be taken...

- The Welsh Government should work with third-sector partners, to ensure there is an appropriate level of support available across Wales for deaf people with additional needs.
- Local authorities should consider people's communication needs when allocating funds for personal budgets and make sure social workers are appropriately skilled to carry out assessments for people who are deaf.

Housing

Housing plays a fundamental role in everyone's life. Our homes and the communities in which they are located directly influence our access to employment, health services and education, as well as our ability to participate in the local community.

During 2014/15 we gathered the personal stories and experiences of people with sensory loss who have used housing services in Wales.

We used this to produce best practice guidance which recommends that housing services should provide deaf awareness training for housing staff, install and maintain hearing loops in accommodation, and consider the effects of background noise when allocating tenancies (Action on Hearing Loss Cymru, 2015).

This guidance will help housing services meet their duties under the Welsh Housing Quality Standard (Welsh Government, 2008) and the Regulatory Framework for Welsh Housing Associations (Welsh Government, 2011) to provide good-quality housing, which meets the specific requirements of the household.

What action needs to be taken...

- All social housing landlords in Wales should deliver support in line with the guidelines in our best practice document, including training all staff in deaf awareness and communications tips.
- The Welsh Government needs to monitor the performance of housing providers, to make sure they are following this guidance and meeting their duties.



Nobody wants to employ a deaf person. Even in the most lowly of jobs. I never got interviews. I just never heard back. I did follow it up with one organisation and asked, “Why have I not got an interview?” And the reply was, “Well you are deaf, you couldn’t possibly manage.”

So I did cleaning for two or three years – it was the only thing I could do. I didn’t like it very much but I did it because I needed to work. It was very hard and very disheartening. Just that feeling that nobody wants you. And that feeling that you cannot contribute anything.

I ended up going back to study with the Open University and heard about a now-closed government scheme which was funding a theatre company devising performances for deaf children.

That was the start of a long career in the arts and I am now strategic director of Disability Arts Cymru. But not everyone is as lucky as I was.

Maggie Hampton, 64, Pontypridd

The Welsh Government must ensure that people with hearing loss have the same access and opportunities to work as everyone else

Employment

A report we commissioned (Boyce, 2015) found that people with hearing loss in Wales face serious barriers to employment due to employer attitudes and inadequate support in the workplace. The report also found that some Job Centre staff did not provide specialist support for people with hearing loss and were unaware of their communication needs.

Action on Hearing Loss is planning to launch a campaign to improve employer attitudes towards employees with deafness, tinnitus and hearing loss. Urgent action is also required from the UK and Welsh governments, the Department for Work and Pensions, Job Centres, and employment agencies, to make sure people with hearing loss are supported in the workplace.

What action needs to be taken...

- The Welsh Government must work with us, and partners such as the Department for Work and Pensions, to ensure that people with hearing loss have the same access and opportunities to work as everyone else.
- Employers should become familiar with the information and resources available to people with hearing loss, so they can be proactive in properly supporting employees who tell them that they have hearing loss.

Access to TV and video on demand

Television services for people with hearing loss have vastly improved in the last few decades. But there are still many programmes that remain inaccessible due to a lack of subtitles or signed interpretation, poor-quality subtitles or inaudible speech.

Many TV programmes remain inaccessible due to a lack of subtitles or signed interpretation

Generally, most subtitling across the UK is only available in English. In Wales, however, the Welsh language channel S4C provides subtitles in both English and Welsh.

In 2014, 78% of S4C's programming was subtitled, although the breakdown between Welsh and English subtitles is not subject to Ofcom targets (Ofcom, 2014). Welsh subtitles are available on some programmes, but the majority of its subtitles are English language.

Research suggests (Wu et al, 2014) that some people with hearing loss in Wales would like to have more subtitles available in Welsh.

We urge all broadcasters to monitor the quality of their subtitling in order to ensure high standards. Technology needs to be further developed in this area in order to reduce mistakes and provide options for language choice.

What action needs to be taken...

- Broadcasters in Wales need to make sure that subtitles are available to both Welsh and English-speaking people who are deaf or have hearing loss.

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Our purpose is to help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way.

To find out more about what we do and how you can support us, go to www.actiononhearingloss.org.uk/wales

Action on Hearing Loss Cymru

Telephone 02920 333 034

Textphone 02920 333 036

Email cymru@hearingloss.org.uk

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On the cover: Maggie from Pontypridd.
Maggie shares her story on page 18.



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