

# Knowing What to Say And How To Say It



**A project discussion**

## **Background**

The project, *Knowing What To Say And How To Say It*, required the project team to grapple with three big subjects: dementia, deafness and communication. This 6-part series is an open account of how the project unfolded and what was found.

The project team included: Sally Shaw of Ideas for Ears, Richard Kilborn of Our Connected Neighbourhoods, and Petra Soltesz, a final year student of University of Stirling.

Sally, Richard and Petra want to thank everyone who supported the project along the way, including all those who took the time to complete the project questionnaire.

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## **Part 1: Planning the project as Covid struck**

When we set about planning our project, we had quite a challenge on our hands. We knew we wanted to get input from lots of people with different experiences and there were all sorts of ways we could do this. After thought and discussion, we created a project plan involving a questionnaire, focus groups, and one-to-one interviews. This combined approach, we believed, would allow us to gather insights from a range of people with differing experiences and perspectives.

However, as it happened, the start of the project coincided with the onset of the Covid pandemic. This quickly disrupted our plans as it became apparent that it would be more difficult to set up meetings with prospective informants and to conduct face to face interviews.

Consequently, we decided that our study had to become more restricted in its scope than we would have preferred. It also meant that our questionnaire would have to work extra hard as it was possible it would be done without the benefit of in-person focus groups and face-to-face interviews to help us explore specific issues more deeply.

Adding to the challenges, as our discussions took shape, we became increasingly aware that the subject of our inquiry would involve getting people to talk about quite sensitive issues. Medical conditions that have serious implications for your life can be hard to come to terms with and we wanted to tread with care. We also recognised that people can take time to adjust and accept the onset of health conditions and consequently they can be a reluctant or reticent about talking too deeply or too openly about difficulties and challenges.

However, at the same time, we felt our inquiry was a worthy one. It could help to identify the best way to find the right words and the right occasion to talk honestly and openly to a partner or friend. It could identify the kind of setting that is best suited to the broaching of concern. And it might help with how to go about finding relevant information from agencies or organisations that have hitherto not been on someone's radar.

### **Getting started**

Given the pandemic, we focused our energy on the questionnaire. We worked to create questions that would draw out insights while tackling sensitive issues with care. We also had to be mindful not to overwhelm questionnaire respondents with complexity of subject matter or volume of questions.

We knew that we wanted to share the questionnaire with local people in the Stirling area, so at this early stage we also began identifying groups of people who we judged would be prepared to support the activity.

## **Avoiding bias and discrimination**

Our focus was on how hearing loss and memory loss are spoken about. But the other issue we wanted to address had to do with the words people use to describe their condition.

People understandably can have significant concerns about any condition they develop. Alongside this, over the years, the careless use of language when speaking about particular conditions has been both stigmatising and discriminating. We recognised that this was particularly apparent with conditions relating to hearing and memory. We also knew it could extend beyond the individual to family and friends

Our efforts to employ non-discriminatory language meant we sometimes faced difficulties in framing questions so as to avoid implicitly stereotyping individuals with hearing or memory issues. We were also aware that the very attempt to use inclusive and non-discriminatory language might lead to the use of words and phrases that to some respondents were overly euphemistic.

## **Striving for the right words**

The words or descriptors that presented us with the greatest challenge were 'dementia' and 'deafness'. Such are the connotations and associations of these words that we were cautious in the way we included them in questions.

With 'dementia', memory issues are only one of a number of symptoms that can present. With 'deafness', there are a multitude of understandings for what it signifies, including one of the strongest, that it describes a person with very little or no hearing. While that is true for some, it is not the case with the big majority.

To avoid introducing distorting elements into the questionnaire, we avoided these words. Instead, we referred to 'memory loss' and 'hearing loss' and in some instances, made it more general still by simply talking about 'memory' and 'hearing'. This left respondents free to make their own connections with dementia and deafness. Which they did.

In many instances, respondents simply used the words 'deaf' or 'dementia' when offering their comments. Others reflected on the meaning of the terms. For instance, several respondents drew attention to the fact that an important distinction needed to be drawn between memory loss, which could have a variety of causes, and dementia, which could manifest a range of symptoms as well as presenting differently in different people.

Another respondent commented:

*"If deafness is stigmatised, how much more so is memory loss! My memory is fine at the moment, but I think it could be difficult owning up to memory loss at work for fear that it could put my job at risk."*

## Part 2: Insights revealed through the questionnaire



*by Richard Kilborn of Our Connected Neighbourhoods*

### **Insights from the survey**

Having put together a questionnaire made up of twenty questions, the next step was to approach a small number of local organisations whose members might be reasonably supposed to have an interest in hearing loss and memory loss.

The Stirling University Retired Staff Association (SURSA) and the Forth Valley University of the Third Age (FVu3a) were obvious target groups, but we also attempted to access a wider demographic by inviting members of the local community, including students and staff members at Stirling University, to give us their views.

Respondents were encouraged to complete the survey online, though provision was also made for those who so wished to complete a paper version of the survey. Particular attention was paid to making the survey user-friendly and ensuring that the language used was accessible as possible.

At the end of the survey an invitation was extended to anyone interested in the issues raised to participate in a follow-up Focus Group discussion or in a one-to-one interview. And mindful that we also had a duty of care to our respondents we also provided details at the end of survey of organisations and agencies offering individual help and support if required.

### **Some initial thoughts on the survey findings**

Given that the survey was conducted in May 2021, at a time when a number of Covid restrictions were still in place, we were encouraged to discover that 60 people in the area responded.

Perhaps unsurprisingly for a survey addressing this type of issue, we received twice as many responses from women as we did from men. The vast majority of respondents, more than 70%, were in the 55+ age group.

Also of some significance – given the nature of our inquiry – was that in answer to the question whether anyone in their close family or friendship groups had some level of hearing or memory loss, two thirds of our respondents replied that they knew someone with hearing loss and almost the same number had a family member or friend with memory loss.

When asked to supply additional information about this, several respondents commented on the impact that this condition had had on family relationships. People also remarked that this had markedly increased their own anxieties that one day they would be likewise affected.

The other finding that we found somewhat surprising was respondents' assessment of their own hearing and memory. When asked to rate their hearing on a scale ranging from 'Good/Very Good' to 'Profound or total hearing loss', more than 60% placed themselves in categories in which there was some, or even substantial hearing loss. By contrast, when asked to assess their memory ability almost half of those who chose to respond currently rated their memory to be 'Good or Very Good'.

### **Talking to others about health conditions**

In response to our question as to how they would be likely to respond if they discovered they themselves had symptoms of a health condition, most people were in agreement as to how they would react and agreed that they would be "happy to share their feelings of concern with someone they trusted". 75% of respondents also stated they would readily seek medical advice. A slightly more surprising finding – given widespread assumptions about the supposed reluctance of some members of the older generation to use digital technology – was that more than 75% of respondents told us that if they discovered symptoms, they would seek out relevant information on their condition on the Internet.

When providing information about how easy they found it to open up to others about health conditions, one or two of our respondents took the opportunity to tell us that it was only as a result of painful experiences that they had gained the necessary confidence to express their concerns. As one person put it:

*"I have had various bad experiences with doctors and family not believing me in the past, but I am now generally able to talk about things."*

Another respondent spoke very poignantly about how, in earlier years, they had developed strategies for not talking openly about anxieties over health concerns. It was only with hindsight, however, that they had come to realise that this was very detrimental.

### **There's more to communication than merely words**

Though our survey was principally concerned to discover more about how people verbally articulated their concerns about hearing and/or memory loss, we were also aware that some would have greater difficulty than others in expressing themselves. When specifically asked what level of difficulty they encountered in this respect, most respondents chose to agree with the statement that they "found it relatively easy to put into words what they were feeling or experiencing". Yet at the same time, most people thought that it was important to recognise that non-verbal language, including gestures and facial expressions, were also significantly involved in the expression – or concealment of what a partner or loved one might be concerned about.

Respondents had some pertinent comments about how revealing a loved one's body language could be. Here is what one person had to say on this issue:

*“Some people don’t want their body language read, which can make things harder. You might be able to tell something is wrong, but not what. And if they don’t want to tell you [verbally] what is wrong, there isn’t much you can do.”*

Another respondent provided an insightful comment on how, faced with the problem of having to communicate something of some importance to another, they used to go through a silent mental rehearsal of how they would express themselves:

*“It takes me a while to understand what I am feeling. Sometimes I need to talk to myself and vocalise my feelings in order to understand myself.”*

When respondents were asked how easy they would find it expressing their concern about both hearing and memory loss, some interesting differences emerged between the two conditions.

In the case of hearing loss, the vast majority (more than 90%) of respondents indicated they would be ‘comfortable’ or ‘very comfortable’ talking with a healthcare professional or audiology specialist about their concerns. This percentage dropped by more than 10%, however, when they were asked how easy they would find it voicing their concerns to a loved one – and the percentage dropped still further if the concern was being expressed to friends.

Clearly there is a considerable level of apprehension associated with the possible consequences of such disclosure. For instance, only a minority of our respondents (just over one third) admitted they would feel comfortable talking about their condition with colleagues or work associates.

This reticence may well reflect the fear of the possible negative repercussions of such an admission. Sometimes, however, it was simply a case of summoning up sufficient courage to talk to others about a condition they felt embarrassed about.

As one person told us:

*“I have used hearing aids for more than six years. To begin with, I was reluctant to reveal that I was deaf. I was embarrassed because I was in my late 40s when I started to use hearing aids and I felt there was a stigma attached to being deaf. But now I don’t care. If I meet someone new and have difficulty hearing them, I tell them I am deaf without hesitation.”*

When it comes to people’s readiness to talk about memory issues, a rather different picture emerges. Even when people had no present concerns in this regard, many of our respondents suggested they would display a much greater degree of caution in voicing their concerns.

For instance, even when talking to a healthcare professional about memory loss, far fewer claimed they would feel at ease than was the case with hearing loss. Similarly, there were a lower number of respondents who claimed they would feel comfortable talking with a loved one about memory loss than was the case with hearing impairment. And the same was true of talking with friends or with work colleagues.

All in all, there was a large measure of agreement between our respondents that the topic of memory loss posed a much greater challenge.

The same disparity emerged when respondents were asked to assess how difficult they would find it when they were out and about in shops and other public places and might have to ask for assistance or support from shop assistants or other members of the public.

In the case of hearing loss, 60% of respondents said they would feel reasonably comfortable in raising their concerns, whilst with memory loss the number was 45%. Readers of this blog will have their own explanations as to why this is the case, but one of our informants chose to provide their own thoughts on why it should be so:

*“If deafness is stigmatised, how much more so is memory loss! My memory is fine at the moment, but it could be difficult to owning up to memory loss at work for fear that it could put my job at risk. Because of the link between memory loss and dementia, I believe that memory loss would be a heavier burden than deafness.”*

Virtually the only situation in which our respondents claimed they would feel a similar degree of comfort in talking about their concerns was when talking to healthcare professionals.

A large majority of those surveyed (more than 80%) indicated they would find it relatively easy talking with an audiologist or with a neurological specialist about their symptoms. This may, of course, be a reflection of the relatively high esteem in which those with specialist knowledge of the respective conditions are held. It may also be evidence of the fact that, once people have taken the momentous step of seeking professional help and advice, this may in itself be a confidence-enhancing move – especially for those who have so far been in a state of denial about the potential seriousness of their condition.

### **Points for consideration:**

1. At several points in this blog we have referred to statistical findings that have emerged from our survey. A summary of the findings displayed as graphs can be found here: [www.ideasforears.org.uk/knowning-what-to-say](http://www.ideasforears.org.uk/knowning-what-to-say)
2. Given that the majority of people seem to prefer talking to healthcare professionals, perhaps greater consideration should be given to ensuring that the routes that guide people to advice centres and support agencies are signalled more clearly than they are at present. It would appear that, in spite of the best efforts of the help-giving

organisations and institutions, too many people are still being hampered in their attempts to seek advice.

3. Part 3 of this series will begin to explore the issue of how sensitive issues such as hearing loss or dementia are talked about and what kinds of additional support and advice might be provided.

## Part 3: Talking about sensitive issues



by Richard Kilborn of Our Connected Neighbourhoods

### Insights from the survey

One of the aims of our project was to discover more about how people might broach the topic of a loved one's failing memory or compromised hearing.

Given the sensitivity of some of the issues involved, we decided that it would be best to adopt a two-step approach. We would first pose the hypothetical question about how a person would be likely to act if they noticed a marked deterioration in a loved one's hearing or memory. We would then follow this up by asking what specific strategies or approaches they might adopt when responding to a partner's hearing or memory loss. It is often a partner who will take the initiative in raising a topic that the other might be disinclined to address.

Once again, there were some interesting variations in people's views on how they imagined they would act in the case of a partner's hearing loss as opposed to memory loss. In the case of the former, more than 80% of respondents stated that it was likely they would have no problems in raising the issue.

This readiness to take swift action by opening up discussion might be partly explained by people's awareness that there are a range of services on which one can call to gain help and support. When invited to give specific suggestions as to how one might persuade a loved one to 'open up' about their concerns, our respondents had a whole series of helpful recommendations.

Many people were eager to stress that a lot would depend on the nature of one's relationship with that other person, how well one knew them and to what extent one might be able to anticipate their likely response. Many also emphasised the importance of showing maximum empathy and of choosing the right moment to voice one's concerns. As one person put it:

*"I would find a private moment and say: "I think I've noticed you're having difficulty hearing - and I know how that feels. Would you like to talk about it? I'd be happy to share my experience, if that. would be helpful."*

Another respondent went to considerable lengths in imaginatively constructing a detailed scenario in which such a 'difficult' conversation about hearing loss might take place:

*"I would ask how their day has been, go in like a normal conversation and initiate a conversation about a previous time in their life when they had significantly better hearing and ask how they felt then. Then bring up a recent time when their hearing*

*has affected their experience and ask how they felt about it. Then I would ask them if they felt like there had been a significant change for them. This would be my method if they were in denial. I would raise this when their behaviour started to impact my life in my normal interactions with them. I would bring up the topic when they were in a good mood, in a relaxing environment.”*

### **The special challenge of talking about memory loss**

One of the most interesting differences in responses relating to preferred strategies for raising difficult issues was that many more people chose to make additional comments about memory loss. This would seem to reflect the high level of anxiety that is felt about medical conditions affecting memory.

Respondents were especially sensitive and empathic when considering appropriate ways of acting if they detected signs of failing memory in a loved one. Their suggestions for appropriate strategies for helping a loved one in these situations showed a good level of insight and understanding, as in displayed in the following comment:

*“I would probably keep an eye on it [ the loved one’s worsening memory] for a short time. If the change was not dramatic, I would try to help the person with strategies for remembering things day to day. If it was a sudden or dramatic change, I would say something sooner. Memory issues can be a serious sign of more than one thing.”*

Some of our respondents had already had experience of having to address the issue of memory loss as a result of having a family member diagnosed with the condition. This was the case with the following person’s father:

*“My father had Alzheimer’s, diagnosed quite early because as a family we noticed an issue and encouraged him to see the GP for a memory test. I know it can be tricky to raise it but because some type of treatments can help to slow the decline it’s better to act earlier than later. I tell people this and explain how an early diagnosis really helped my Dad. Waiting till it’s too late won’t make the problem go away but might mean it is too late to treat. Worsening memory can be a symptom of other conditions e.g. Parkinson’s that benefit from treatment and support. I’m not the kind of person to stick my head in the sand about such things”.*

What was especially striking about the comments in relation to recommended strategies for talking about failing memory was the sheer diversity or what was suggested.

Almost everybody who chose to comment, however, stressed the need to match the proposed strategy to the character and temperament of the person affected. Several respondents emphasised the importance of choosing the right time and setting for such a conversation.

People with experience of talking to those with hearing loss mentioned that it would be vital to hold the conversation in an optimal acoustic environment. Other respondents also stressed that – however one went about broaching the subject - one should show maximum respect for the individual:

*“I would only raise it with close family, and it would be at a time when we were unlikely to have interruptions.”*

*“I would make a general comment, maybe keeping it in relation to myself. [I would try] to open some form of discussion and lead into it that way. Again, I would only raise this in a private quiet place and when we were on our own.”*

Mindful of the need to be empathetic, one or two respondents commented on the advantages of adopting a gently-gently approach and of cueing in to all the signals - both verbal and non-verbal – that the other person was giving you:

*“If the person is aware of the problem and body language shows they are anxious I would first ask, if they were ok and ask if they wanted to mention it to their doctor. If they didn't appear to be aware, the next time an example of memory difficulty occurred, I would gently say [that] this has happened a few times now or 'I'm worried you're forgetting things'.”*

All these suggested strategies are commendable, and they all fall in line with the advice given by the Alzheimer's Society. The golden rule is to avoid any suggestion that it is some 'affliction' that one is confronting and to ensure that one uses positive language.

As the [Alzheimer's Society guide](#) puts it: “Always use language that dementia is not the defining aspect of a person's life. See the person, not the dementia”. The same guide goes on to give the following advice about the need to use positive language when talking about dementia:

“The way we talk about dementia has a direct effect on how people living with the condition feel. It can also have a profound effect on society. After all, the words we use affect the way we think, and the way we think affects how we behave. For those living with dementia, using words or phrases that label, belittle or depersonalise people can have a big impact on them and their family. It changes the way they feel about themselves, shaping their mood, self-esteem, and feelings of happiness or depression. It can also change the way other people think about dementia, and increase the likelihood of a person with dementia experiencing stigma or discrimination”

The advice given above is designed to make all of us more aware of the need to choose the right words in what are very sensitive situations. The crucial point to bear in mind is that the person who you are speaking about should be recognised as someone deserving of the highest respect.

One of the ways of showing respect is by putting oneself in the shoes of the person with memory loss. Much of this advice is reflected in responses given by our survey respondents.

A strategy that several of them recommend when starting a conversation on 'memory issues' is to first make reference to one's own memory before then inquiring whether the other person faces similar challenges:

*"I'm finding that I can't remember so much with age. How about you?"*

*"I'd say I felt that my own memory was not as good as it used to be and maybe the same applied to hers".*

*"It's more difficult to remember things when you get older, isn't it? Nowadays, I seem to have a lot of senior moments and I suspect the same is true for you too. Have you thought of getting yourself tested?"*

As well as the need to demonstrate empathy with the person with memory loss, several of our respondents stressed the importance of carefully planning the occasion when any conversation about memory loss would take place:

*"It would very much depend on the circumstances and the person involved. It would need a lot of thought beforehand."*

One or two people favoured a more indirect approach when raising concern about a family member's worsening memory. This approach would involve first talking matters over with friends and family of the person affected. One person went into considerable detail as to how they would proceed:

*"I would not raise concern with the individual but would rather raise it with friends and family. There could be a discussion on how to most effectively interact with the individual with worsening memory loss. I would bring up the topic when the other person is calm but not necessarily when everyone is in a group together".*

### **Points for consideration**

1. There would appear to be a lack of clarity about identifying the early signs of memory loss. Given the special challenges posed by talking about memory loss, a greater effort should be made to provide adequate information to the public on how to identify these signs and on how and where to seek advice.
2. In Part 4 of the series, we will be considering what kind of obstacles people might have to overcome before raising the subject of hearing loss or memory loss with a loved one.

## Part 4: Obstacles to overcome



*Reported by Richard Kilborn of Our Connected Neighbourhoods*

Most of us are already familiar with the difficulties of talking about certain topics with a loved one. Indeed, some people find they are able to talk more freely about intimate aspects of their lives with a total stranger than with someone from their close family circle.

It is also generally accepted that, when we do pluck up the courage to share something with a friend or family member, we will often do a certain amount of self-censoring.

We persuade ourselves that – maybe out of deference to the other person, - we will choose not to mention certain issues. Sometimes, this might simply indicate a lack of courage on our part in not wanting to face up to uncomfortable truths. Sometimes the self-censoring will be out of respect for how the other person might react to what we have to say.

### **What holds people back from engaging in this sort of conversation?**

Given the particular difficulties that are acknowledged to be involved in talking with someone about hearing or memory loss, we were also interested to learn more about the specific reasons as to why a person might hold back from starting such a conversation.

We therefore introduced into our survey a question that offered respondents various possible reasons for holding back. We invited them to select the two reasons most likely to prevent them from saying they were concerned about the other person's hearing or memory. The reasons we offered ranged from "Not finding the right moment" and "The fear of a negative reaction" to "Not wanting to cause offence" or "Not knowing what to say".

Being given a range of options had the predictable result that most of our respondents simply went along with the suggested reasons and indicated that these were the ones that were mostly likely to hold them back. There was also widespread acknowledgement that it would be difficult to find the right time for such a conversation. And many agreed that – even if they did pluck up the courage to say something – they would fear getting a negative response.

The only case in which people were disinclined to accept one of the reasons given was when we suggested that the reason why they might not initiate a conversation with someone with hearing loss was "because they did not know what to say". Less than a third of our respondents agreed with this proposition – once again underlining our general finding that people had fewer misgivings about talking about loss of hearing than loss of memory.

On looking through some of respondents' additional comments, it soon became clear that it was not so much that people were 'lost for words' when verbally interacting with someone who appeared to be struggling with their memory. It was more that they had decided beforehand that there were certain things that were better left unsaid. Evidence of this is also proved by the survey finding that showed that a significant number of people admitted they would not broach the issue of memory loss for fear of causing offence

### **Preferred terms and words or phrases considered off-limits**

One the main aims of our survey was to get a better idea of how memory and hearing loss are talked about and to discover what impact the use of certain words and phrases has on those who are either concerned they might be affected by these conditions or have already received a diagnosis.

To these ends, we devoted part of the survey to checking on how people react to terms that are frequently used in general parlance to describe the respective conditions. We also them to differentiate between terms they themselves had used and terms they actively disliked.

Predictably enough, when it came to an assessment of the way in which memory loss is talked about, people generally favoured straightforward, neutral descriptors such as 'memory loss' or 'forgetful'. And more than 60% of respondents said they used the term 'senior moment' although about 30% of respondents also disliked this. There was active dislike also for the term 'dodgy memory' and 'easily confused', but the highest levels of dislike were for 'wandering mind' and 'muddled thinking'.

It was gratifying to see the extent to which many of our respondents were sensitively attuned to the associations and connotations that words can have for those most directly affected by these conditions. Indeed, one or two people reminded us that 'muddled thinking' is certainly not the sole preserve of those who have memory problems!

One person had some very perceptive comments to make regarding the need to make a careful distinction between terms used to describe difficulties in cognitive processing and terms that relate more specifically to dementia and memory loss:

*"I wouldn't use 'muddled thinking', 'easily confused' or 'wandering mind' to talk about memory issues. I would use them more [in relation to] the ability to process thoughts and I would use 'wandering mind' to describe being easily distracted. To me, memory and processing ability are different things, though people with dementia may experience difficulties with both."*

When people were asked to comment on words and phrases they had personally used to describe hearing difficulties, there was a similar pattern of response as with memory issues. Words that belittle or trivialise were avoided, in favour of words that were more objective or respectful.

Just as with memory loss, respondents displayed a high level of sensitivity to the ways in which hearing and deafness issues are talked about. Carefully directed questions which gave the person addressed the opportunity to describe their hearing status were considered as superior to those that cast the person as 'victim' or 'sufferer'. The simple but effective question: "What is your hearing like?" was thought to be an excellent way of getting a conversation off on the right foot.

Just as with memory, terms that are more formal and clear-cut were generally preferred. Thus, terms such as 'hearing loss', 'hearing impairment', 'hard of hearing', 'hearing difficulties' and 'deaf' were used more commonly than those that are more colloquial and could be considered to have judgemental or negative overtones, such as 'dodgy hearing' or 'selective hearing'.

One should perhaps remember in this respect that certain terms that might well have been used with some frequency by earlier generations are nowadays very properly considered to be beyond the pale. Evidence of this is provided by one of our respondents who had the following comment to make:

*"Deaf as a post – I personally don't like this term, but I happen to know that it was commonly used by my parents' generation."*

### **Points for consideration**

1. We perhaps need to improve communication between those who are affected by hearing and memory loss and the various organisations geared up to provide help and support. Existing channels of communication should perhaps be reviewed with a view to making the information provided more user-friendly.
2. The next blog will focus on some of the suggestions and recommendations that our respondents made regarding how to open up discussion about hearing loss and memory loss, including some thoughts on how certain communicative challenges might be addressed.

## Part 5: Promoting more open and informed discussion



Reported by Richard Kilborn of Our Connected Neighbourhoods

### Opening up the discussion

The majority of the questions that we included in our questionnaire were of the multiple-choice variety. This was to make the questionnaire more user friendly and to encourage a greater response.

The last five questions in the survey, however, were of a more open-ended type and provided respondents with the opportunity to give more fulsome comments. Some of these comments proved to be highly revealing, especially regarding people's thoughts on the kind of language that was appropriate to discuss difficult and sensitive issues.

The first of our open-ended questions had the following wording:

*'When people you know talk about those who have hearing or memory loss, has anything struck you about the language they use?'*

In framing the question in this way, we were making the assumption that people had already had experience of being in this situation – or would at least be able to envisage such a scenario.

What was striking about the responses we got, however, was the degree of understanding that people had of the types of language that might prove harmful or hurtful to someone with hearing loss or memory loss.

For instance, respondents drew attention to the likely frustration that those living with these conditions would experience if they were spoken of in condescending or derogatory terms. Several people expressed concern about how demeaning it must be to be talked about in a way that infantilised the individual or questioned their intelligence:

*"They speak as if the person is not there. It is as if their intelligence is in question."*

*"What strikes me is the language can sometimes sound derogatory or even dismissive of the serious impact the loss could have on that individual."*

One or two respondents also commented on how painful it must be if other people reveal a pitying attitude to someone with hearing or memory loss, thereby encouraging the belief that this is the defining feature of their being:

*“I don't like how people close to me talk about hearing or memory loss in such way that they pity them and make it the central aspect of their character.”*

People living with various forms of disability have expressed similar dissatisfaction when they are spoken about in such dismissive terms. A recent survey conducted by the Leonard Cheshire organisation found that many are needing help to understand what words can cause offence. As a [Leonard Cheshire spokesperson](#) commented:

*“We found that 46% of all disabled Brits feel regularly ‘ignored’ or ‘overlooked’ by non-disabled people due to widespread use of inappropriate or demeaning language.”*

Our respondents were also eager to underline how the type of language used to talk about hearing and memory loss depended on additional factors such as the precise relationship between those involved in the conversation.

For someone in a close personal relationship with the person with hearing or memory loss, the language used can frequently be emotionally charged. This is understandable given the various challenges that living with hearing or memory loss can give rise to. By contrast, those working in a professional capacity will tend to be more constrained and circumspect in their choice of language. As one of our respondents commented:

*“Ordinary people, when talking about family members, neighbours etc who have hearing loss often express frustration. Those in professional capacities often seem to be working hard to use the terminology that is currently acceptable.”*

This difference in levels of formality also extends to whether the communication is in spoken or in written form. The latter will tend to favour what might be seen as more ‘acceptable’ terms in describing or referring to medical conditions. One of our respondents picked up on this difference in the following comment:

*“When talking about themselves, people tend to say they have ‘trouble with memory’ or are ‘a bit hard of hearing’ rather than using terms such as ‘hearing impaired’ or ‘memory loss’ which I think are more medical terms and are used more in written communication than spoken.”*

Finally, several people in the survey commented that many individuals, in order to avoid causing offence, resort to talking euphemistically about these conditions:

*“They often use various different terms as they don't want to offend anyone by using inappropriate language.”*

*“Generally, I think people use euphemisms, rather than directly talk about someone being deaf or having dementia.”*

On the other hand, some respondents recognised that the use of euphemistic terms can come at a certain cost. In the endeavour to show consideration, one finishes up not showing sufficient respect for the person. In the words of one of our respondents:

*“The words that they use are clichéd and not often descriptive of the person.”*

The diverse responses we got to this question about the language people use in talking about hearing and memory loss brought home to us the sheer difficulty of striking a balance between, on the one hand, being open and honest and at the same time showing respect for the feelings of individuals. As one person put it:

*“I often feel that people, including myself, sometimes struggle to find the appropriate words and [I know that] I can sometimes sound a little patronising.”*

### **Putting yourself in someone else’s shoes**

All of us know how difficult it is trying to put oneself in someone else’s position. This is especially true if the other person is living with some form of disability. The second of the more open-ended questions in our survey asked respondents to imagine what some of the main challenges would be for someone who has worried about their hearing or memory, particularly when raising their concerns with other people.

As one might have expected, there were a wide range of responses to this question, but people tended to focus on three or four main areas of challenge. Several of our respondents referred to the various levels of embarrassment or shame that an individual with hearing or memory loss might feel when talking about their concerns. In the words of one respondent:

*“[They probably feel] embarrassment, not wanting to bother someone with their problem and a sense of inadequacy at expressing themselves.”*

A significant number of our respondents also felt that one of the most challenging aspects about voicing concerns would be fear or apprehension about the consequences of so doing.

For instance, one person suggested that one of the fears that someone would face when opening up in this way was that of *“not being taken seriously as a person”*. Another thought that the fear would take the form of not having one’s concern properly acknowledged.

Several of our respondents were of the opinion that it would be people’s fear of being thought stupid or lacking in intelligence that would hold them back from opening up about their concerns. Another respondent, however, felt that the fear would be that of *“exposing [their] vulnerability”* and thereby heightening the risk of their being stigmatised.

### **Communicative barriers, including that of denial**

One or two people in our survey suggested that the biggest hurdle for a person with concerns about their hearing or memory would be admitting to themselves that they had a problem in the first place or being honest about how serious their condition was. For instance, one respondent observed that the underlying reason for some people adopting a head-in-the-sand attitude was the fear about what the economic consequences of full disclosure would be.

Another respondent felt that there would be a significant difference in the readiness of people to open up about their condition, depending on whether the issue was one of hearing or of memory. This person thought that, whereas most people would be prepared to talk more or less openly about hearing loss, a person experiencing memory loss would be much more cautious and circumspect. They might even refuse to admit they had any issues at all, since the prospect of having to talk to friends or family members about it was just too painful:

*“The reduction in the ability to hear can be rectified, whereas memory loss is more likely to have [people] thinking it’s dementia. So, I think that people are more likely to get their hearing tested or get hearing aids. But saying that they have memory loss can cause relatives & friends to ‘fear the worst’. So, they may be more likely to minimise memory loss.”*

Finally, on this question of what would help or hinder a person in talking openly about their condition, one or two respondents raised the issue of the role played by the other person involved in a conversational exchange.

One of our respondents, for instance, was keen to emphasise that the success or failure of such an exchange would depend on the readiness of a sympathetic listener to hear and understand what the other was attempting to convey:

*“I think that people can sometimes feel really awkward when someone is telling them about health concerns. So, it can be a challenge to get someone to listen and take your concern on board. It’s too easy to dismiss someone’s concerns. I also think that no one wants to be seen as not being perfect and that people might think less of them if they have hearing or memory loss.”*

Another respondent went into considerable detail concerning do’s and don’ts when conversing with someone who has hearing loss:

*“When you speak to [someone with hearing loss], take your time, don’t rush them, speak slowly and carefully. If you can’t hear well it can be hard to follow what someone is saying. It takes a while for the brain to catch up with the sense of the words, as it were. So be patient, given them time. If the deaf person is looking*

*confused, repeat what you're saying to give them another chance to hear and understand what you are saying".*

In some cases, however, the challenge of getting someone to listen and take one's concerns on board can clearly prove to be difficult. One respondent shared their experience of wanting to raise their concern but all their efforts failed:

*"I have found that it's difficult to get anyone to take you seriously when you are, say, under 50 years of age. You get palmed off on such a regular basis that you just give up trying to get help."*

### **Points for consideration**

1. More thought needs to be given to how people can be helped to talk openly and honestly about hearing and memory issues.
2. When respondents were asked about how things might be improved, they were generally able to come up with a series of generally helpful suggestions. The challenge remains that of knowing how to feed these insights through to healthcare organisations and agencies that provide help and support.
3. In the final part of this series, we will be exploring ways of encouraging the use of more positive language when talking about dementia and hearing loss.

## Part 6: Encouraging the use of positive language



by Richard Kilborn of Our Connected Neighbourhoods

The penultimate question in our survey asked respondents to provide recommendations and advice concerning the use of positive language.

Respondents were asked to imagine they were preparing a guide to encourage the use of positive language when talking about people with memory or hearing loss. They were asked to give their top three recommendations, in each case indicating whether the advice related to memory or hearing.

The responses we got to this question in many ways fell in line with views that people had expressed throughout the survey. Whether talking about a person with memory loss or hearing loss, our respondents were clear that absolute priority should be given to treating the other person with dignity and respect:

*“Please understand that the person is still the same person, whether they have memory or hearing loss.”*

*“You need to talk about the disability, not the person.”*

People were especially conscious of how important it would be to understand the feelings of someone with memory loss whose cognitive capacity was no longer what it once was:

*“Remember that they [persons with memory loss] are a real person who may not realise that the way they act or think is contrary to what they did in the past and they do not realise that they are acting or speaking differently.”*

The other recommendation that featured prominently was the need to accentuate the positive. Respondents came up with various ways of expressing this:

*“Focus on what they can do rather than what they can’t.”*

*“Pay attention to the part of their life that still functions well.”*

*“Encourage what they can do.”*

*“Think about solutions as well as problems.”*

One or two respondents also recognised that the very attempt to be positive, forward-looking and affirmative might prove in some cases to be counterproductive. It might gloss

over a person's real sense of loss, so some respondents were keen to sound a note of caution:

*"[The use of] positive language may be seen to dismiss or minimise the problem and could even deter some people from seeking help."*

*"Be positive, but don't be cheesy. This applies to both memory loss and to hearing loss. No-one wants over-inspirational phrases when dealing with a health condition."*

### **The need for honest and straight dealing**

When asked to comment further on how one might promote the use of positive language, several people stressed the need for honest and straight dealing:

*"Be honest and use real terms such as 'deaf' and 'dementia'. Call things what they are."*

*"Don't pretend the loss isn't there or downplay it. Be straight with people."*

Being honest and respectful with people with hearing or memory loss also includes a willingness to provide the kind of practical help and support that can be invaluable to someone whose confidence might be compromised.

Simply telling a person that help is out there can in itself be reassuring. Likewise, asking them in what particular way one can help them can remind the person that they still have agency:

*"Ask a deaf or hard of hearing person what you can do to help them hear better."*

### **Minding one's own language**

Another recommendation that was made, in one form or other, by several of our respondents was the need to be careful in one's choice of language when referring to the respective conditions:

*"Keep it natural. People use different language when talking than when writing."*

*"Use the correct terms e.g. hearing loss and memory loss"*

*"[With hearing loss] use person-centric language i.e. ask how they would like to be referred to".*

As well as paying attention to the kind of language one should employ in these situations, respondents were also alert to what one should attempt to avoid. Words and phrases that implicitly or explicitly minimise or trivialise the respective condition should be rejected. And by the same token, one should be aware of the potential hazards involved in the use of humour in the attempt to lighten the tone of such conversation:

*“NEVER joke about someone being unable to hear or remember.”*

*“Remember that the person is struggling with the loss and do not belittle them.”*

All in all, people’s recommendations to encourage the use of positive language reflected a high level of empathy with those seeking to come to terms with these conditions. One of the key recommendations was to use language that prioritises the condition but does not contain any suggestion that the person is defined by the condition. As one respondent succinctly noted:

*“Think of it as a medical condition, rather than a disability.”*

### **Reasons for being cautiously optimistic**

What was gratifying about the response we got from those who participated in our survey was that it showed how willing people were to give serious thought to some of the issues raised. As one respondent commented:

*“There needs to be more discussion about both of these conditions [hearing loss and memory loss], so there is less perceived stigma attached to both.”*

What was also encouraging to learn was that several respondents had taken the opportunity to reflect on the implications of these issues for wider society, especially on how the challenges of living with hearing and memory loss are being addressed.

One person, for instance, stressed the need for much greater attention being paid to *“looking after memory health”*. The same person was sceptical, however, about whether healthcare professionals were doing enough to help people to manage these conditions:

*“Management of these conditions is really important. GPs tend to go for the easiest diagnosis, particularly if you are of a certain age. they will dismiss your concerns if you are deemed too young”.*

### **What next?**

The Project Team recognised from the outset that a questionnaire would have its limitations, especially as it was conducted at the height of the Covid pandemic. However, it

has served a very helpful purpose in allowing identification of some issues that could benefit from more awareness and attention.

We also realise there is a great deal more that could be explored. For instance:

1. Given the increasing communication difficulties that arise as a result of hearing or memory declining, we would have liked to discover more about the impact hearing and memory difficulties have on partners and close family members. Interviews with a spouse or a partner could have helped reveal some of the communicative challenges faced when life priorities had to be re-examined.

Questions we might have asked include: How does one prepare oneself for a difficult and challenging conversation when it first becomes apparent that a loved one has problems? How does one go about equipping oneself with the necessary information about the condition? And perhaps most significant of all: Does it get any easier over time talking about the condition affecting one's partner?

2. We would have liked to understand more about the state of mind of those who develop hearing or memory loss. How quickly do they become reconciled to living with the condition? How does this alter the way they talk about it and the language they feel is acceptable or unacceptable for them and/or others to use?

Also, is there a noticeable difference in how they feel before and after diagnosis? A diagnosis forces recognition that you are now living with what is a potentially life-changing condition – what does this mean about your sense of self and how you view and talk about symptoms and difficulties.

3. We were interested too in the perspective of family and friends around when and how they noticed significant changes in their loved one's readiness or ability to talk about hearing or memory loss as their condition developed. For instance, how did things alter before and after diagnosis?
4. Beyond this, we felt there is a need for much deeper, wider discussion about the kind of language used to talk about hearing and memory. Our findings suggest that people want to choose words that will not offend or imply disrespect.

More discussion would help to explore choice of language and how it might change in different contexts. For instance, could healthcare organisations and support agencies reach and assist more people if they tailored the messages they convey. For example, in our questionnaire, rather than asking "How severe is your hearing loss?" or "How much memory loss do you have?" we asked 'What is your hearing like?' and 'What is your memory like?' It worked well.

5. Related to this, another possibility for future work is to set up some form of collaboration with health education authorities and other support groups to ensure that all materials designed to raise awareness about hearing and memory loss are couched in accessible and inclusive language.

Through our questionnaire, we saw that individuals and families have sometimes faced an uphill struggle trying to make sense of information leaflets that make excessive use of specialised medical vocabulary. For some, this proved to be a very challenging experience, especially coming at a time when people's general level of confidence was already at a low ebb. It would thus be highly desirable to make certain that all informational materials produced in future are genuinely user-friendly.

6. A final project idea relates to the role played by those participating as a 'concerned other' in any communicative exchange on the subject of hearing or memory. We have already commented on how people living with memory or hearing loss are often far more apprehensive about things than they once were.

These feelings of uncertainty may, in turn, have a marked impact on their communicative ability and their readiness to express in words what they are concerned about. All the more reason, therefore, in any communicative exchange, to do one's utmost to be an attentive and respectful listener. What one needs to bear in mind is that the other person involved in the conversation is always playing a vital part in facilitating the exchange by responding empathically to non-verbal signals given by the other person.

### **Final reflections**

The small team involved in carrying out the survey fully recognised that there is much more that remains to be done in raising awareness about many of these issues. Among many other things, the questionnaire has shown that finding the right language to talk about these matters is by no means the sole concern of those who are having to come to terms with living with these conditions.

It is also something that arguably should feature more prominently in the wider attempt to foster more caring and understanding attitudes towards those in our society who are confronting particular challenges. The creation of a genuinely inclusive environment is within our grasp, provided that sufficient number of people are committed to achieving this goal.

Sensitivity to language lies at the heart of what the current project has been all about. Finding the right words to talk about one's own condition is difficult enough. Being careful about one's choice of words when talking to or talking about someone with hearing or memory loss is equally important.

We should continue to build awareness of hearing and memory loss and related to this, help people become better equipped to talk more openly about their fears and apprehensions concerning hearing and memory conditions.

We should also remember that people are individuals who will have their own preferences and judgements. They may not wish to share their fears or disclose when they are having difficulties. Everyone has the right to dignity and privacy and that must be remembered and respected in any endeavour to have an open conversation.

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### **Get in touch**

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