Deaflink

END OF LIFE RESEARCH

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Contents

METHODOLOGY

Deaflink invited feedback from our members for 9 weeks through September-October 2016. We offered one to one interviews and 75% of the input from people who had recent experience of supporting someone in receipt of palliative care were through this method. British Sign Language (BSL) adapted paper questionnaires were also available and online questionnaires (with BSL video clips) accessed through our website.

We supported the research by going to our group and forums and raising awareness of the research and of the topic itself. In recognition that we were raising a potentially difficult topic with people we research local services available for people requiring emotional support and how BSL users would access them, from this we produced a leaflet of services.

We had 31 responses - 21 D/deaf, 8 hard of hearing (HoH) and 2 Child of Deaf Adults (CODA). The Online questionnaire was open to anyone and we did have replies from people living outside the area.

We asked people to answer questions relevant to their recent experience. We had 3 different questionnaires:

- **Group A** for people receiving End of Life care, we had 0 replies.
- **Group B** People with end of life care experience in the last 2 years. In this group we had replies from 5 people, 3 BSL users, 1 HoH and 1 hearing child of D/deaf Father.
- **Group C** People with no recent end of life care experience. We had replies from 18 BSL users and 7 HoH and 1 hearing child of D/deaf Adults.

BSL users generally do not feel comfortable communicating in written English. For the purposes of clarity we have amended some of the replies to into clearer English, where possible checking with the author if the amendments were correct.

To assist in comparisons we have colour coded replies – BSL user replies will be in black font, the HoH responses will be in green, the CODA replies are in dark red.

SUMMARY OF FINDINGS

In this section we will focus on two sections. The first will identify the key points from the interviews with people who have cared for or are caring for a person experiencing 'end of life care'. The second part will pull together the thoughts people had about their own end of life needs.

PEOPLE WITH EXPERIENCE OF CARING

The person who was hard of hearing was not interviewed, they chose to complete the online questionnaire.

At the start of each interview we asked the person 'do you know what 'end of life' or palliative care is? The responses highlighted that, matching the people with no experience of caring, the carers generally did not know what it was "No never had one like that before" "no?" "Yes, it's PALS". When we explained what the services were we then asked how long they had been receiving palliative care? The answers ranged from several years to 2 days.

They received the support they needed?

Every one of the respondents said that they felt that the person dying had received the support they needed. One of them gave an example of good communication - "They kept informing me with information that's good. I don't feel left out," in reference to a psychologist service.

When replying to this question the examples were often focussed on medical treatment "staff work there look after everything him, feed him, and give tablets and things" or "Very good support from GP and nurse" and there was a consensus of everyone had been helpful. However their stories show that there had been several years of struggle for diagnosis and looking after their loved one i.e. "She had been having accidents, not fair and too much of mess, hard work." In one case asking a medically trained next door neighbour for help "So I went to next door, Sandra she work as nurse for cancer in Freeman Hospital, asked her to do me a favour to come and have a look at my husband as he was not very good,".

The response to this question is from the perspective of the carer and therefore less likely to be negative as they would, naturally, hope that the person they cared for received the right support in the last few days and months of their lives. There was consensus feeling of 'they only want me' 'he doesn't want them' and did this mean that people were less likely to look for help or support as they felt they should provide the assistance?

When reflected with the general responses there is a theme of fear and communication barriers, a higher percentage of BSL users wanting to die at home.

> “either my daughter or I needed to be present at all visits to facilitate
> communication and to try to make sure that my Father's needs were
> being met.”

Did this affect the carers request for help? Or to communicate or to understand the situation or even perhaps a lack of knowledge of what was available? Few of the carers could identify services, other than hospices, that were there to help them.

None of them suggested that communication with an interpreter was a regular occurrence. Throughout the research there were examples of when communication was a problem, for example, “During a visit I encountered Health Care Assistants shouting at him. I explained that he is profoundly Deaf they were apparently told that he was **Hard of Hearing”.** Or the partner of a patient who had been in hospital for over a week having a conversation about switching off his partners defibrillator machine, we asked *at any stage did you have a BSL interpreter or ask for one?* “No I haven’t asked for an interpreter, I know because interpreters can’t come emergency, I know most of them always work.”

In terms of improvements the suggestions were, understandably, to use appropriate communication methods e.g. to use an interpreter (preferably one they know and have used), not to use the telephone. Another common element was a need for improved deaf awareness and an understanding of the distress that is caused by lack of communication – from medical staff, from chaplaincy staff.

Different Services

Whilst other services were mentioned the main agency referred to was Social Services, there were a few references to Social Workers who helped them access other services and equipment.

> “Newcastle social worker, had a lot from her but she left because of the cuts”

Recent cuts to local authority budgets has seen the closure of all specialist sensory support units and result is that there is one qualified Social Worker who can use BSL in the North East. To qualify for social work support today D/deaf people must have additional needs. In the past a deaf person could rely on a Social Worker who would assist in communication with other agencies, co-ordination of services, understanding events and arranging funerals and helping with administration. There are no statutory agencies who currently offer these services to the deaf community.

There are fundamental assumptions regarding the level of BSL users understanding and knowledge of services available. If they are not already aware, and no-one takes the time to explain options, then access to some services will always be limited as promotional information if not accessible.

> "As a BSL Interpreter I have worked with terminally ill deaf people and
> have no knowledge of any mention of Hospice, **ever**."

Dignity and respect?

The majority of respondents had high praise for medical staff and felt that they 'did very well', they did the best they could' and there was a recognition that staff were very busy. There was also an acknowledgment that in some cases that the patient was not easy to look after.

Each one of the respondents had expressed using the services without interpreters and as this is extremely common for BSL users they do not necessarily identify this as an issue or problem.

> "No bad experiences, just natural, not hate. Just want someone there like
> interpreter that all."

The hearing daughter of deaf parents said:

> "only his basic needs were being met so how could he be treat with dignity
> and respect he couldn't communicate his needs"

The examples given by the interpreters in the Professional Observation section of this report highlights the affect that communication will have on an individual's quality of care and experience at end of life stage.

- "He had no control or decision making at the end of his life."
- "Towards the end she was unable to communicate all. But she was given the chance to. She stated that she had had a good life and accepted her pending death."
- "She told me she had cancer but she said no more, only that her family did not want anyone to know. I felt it was taken completely out of her hands"

How can this be improved?

- Specialist BSL Interpreting services – provided by qualified and chosen/preferred interpreters
- Ward rounds/discussions only taking place when an interpreter is present
- Deaf awareness on the wards
- Accepting that a deaf person has the right to be next of kin and provide appropriate communication support to them
- Contact through Text messaging or other format chosen by patient/family

How involved were they in decisions about their care?

80% of the respondents identified that their loved one had dementia and this affected how much the patient was able to be involved in their own care. There is little information about what was discussed at early stages of ill health with the exception of a request to be cared for at home. There were examples of the services relying on family members to communicate with the patient.

> "I had to take time off work and plan my hospital visits around meals to make
> sure he could communicate what he wanted to eat."

A professional interpreter observed the following 'Interpreters were rarely used during her illness rather her deaf family wrote messages to doctors, etc. and withheld info from her. She could not stand up to them.'

The issue of involvement in care is a concern. Not only are patients and carers denied information by not using interpreters but this is also removing choice and control. Medical professionals are often reliant upon family and friends communicating with the patient – how do the medical professionals know what is being communicated to the patient? Most family members will not be qualified interpreters.

This also highlights the issue of power imbalances, whether patient or carer, if the medical staff rely on family/friends to interpret then this means that the needs of the deaf person is open to being disregarded. There are examples of where deaf carer wanted an alarm to notify him if partner was in need, the partner did not want this – did anyone spend time discussing concerns with carer, explored alternatives? A patient whose deaf family withheld information from her, nor did they inform anyone of her stay in hospital and she did not receive visitors – was this the choice of the patient, advised by the medical staff or the choice of the family?

Support around their communication needs?

Communication is a common thread through all of the research. From the carers perspective it affects how much they understand or feel involved in their loved ones care.

> "No BSL interpreters in the hospitals, only lip-read. I nodded sometimes"

There is another the example where a carer is struggling to communicate with their hearing parent

> "(Mother is hearing) Not very good I can't, I don't understand at all, lip-reading
> no good at all. Lip-reading, her teeth is gone. We tried fingerspelling, can do

> some alright but sometimes she was stuck on fingerspelling as her brain shut down, struggling but can't. Same my wife (also Deaf)" They go on to say "She telling less and less to me, most of the time I tell her but her response is not much."

Failing to recognise the need for and to provide an interpreter to support the communication between mother and son is having a massive impact on the relationship, with the son saying he goes to see his mother fewer times and stays only 5 minutes.

How could communication have improved?

- "Interpreters should be available in emergencies, find someone on 'stand by' through the day.
- "We want the same interpreter (*they*) know all his background."
- "Not enough news, know it's hard, not easy!
- "Deaf awareness and understanding of the need for specialist interpreters."

The health care professionals are reliant on interpreters to communicate with BSL users. Note writing and lip-reading are limited. Many people do not appreciate that BSL users rarely have a good comprehension of English, it is a different language. The interpreter will assess how much the BSL user is taking on board, do they understand what is being said? Do they know the options available? And the interpreter will ensure that the health professional has answered all questions. Using familiar or preferred interpreters should be used during this time as it gives people reassurance and comfort that they know it is someone they can understand and trust.

There is also a need to recognise a culture within deaf communities of deference to hearing people. An acceptance, without complaint, of services offered.

Communication, with BSL users, without interpreters, is meaningless

Were cultural needs met?

60% of respondents said yes, their needs were met – but with reference to their religion, or that they didn't have any needs. The 40% who felt that their needs were not met felt that this was a lack of deaf awareness.

> "On the ward they seemed to panic and didn't know how to cope with him and his deafness"

Preference about where they would like to die?

Only one person said that their loved on had any preference (to die at home), and they did not die where they wanted to (hospital) and this was because of the specialist treatment required in hospital. The majority never mentioned it only the burial/cremation plans. Given that they were receiving palliative care this seems strange that they have not had discussions about where they would prefer to die, perhaps a lack of knowledge about the options available is a factor.

Were they made comfortable in the place where they died?

One person answered this question and they said, yes, the patient was comfortable. In explaining this others felt that they didn't know.

This question is, again, quite difficult for a carer to reply to, it is their perspective of events. One person said that her husband died peacefully at home and yet the description of events of that day doesn't necessarily support this. Her husband went to bed feeling ill and she checked on him regularly over the next few hours. He asked for a doctor and, before medical professionals arrived, he died.

How involved were you in decisions about their care?

The replies below highlight the issues:

- "Most of the time I was in the decisions"
- "They contacted my wife's mother! so I told them no it's me you need to tell me direct, not her"
- "Back to ward 19, but getting worse and worse. Before that, the doctor knew he had a weak heart, said 'do you want to switch off his defibrillator?' I was unsure and said no not yet. One week later, other doctor came in and said he still have a very weak heart do you want to switch off the defibrillator?' I was unsure I rather someone tell me, his son was quiet, I looked at son said nothing."
- "I've asked the staff ward sister team, I asked what treatments, arrange what, what best for her etc. I asked and asked. Been regularly writing, emails etc. Been writing to give information about what I will do, can do, monitoring care etc. up to the doctor to decide, I don't see the doctor. Wrong time, wrong place. What plans? Inform me when? carry on tablets or plans in the future, etc., nothing."
- "Especially the hospitals, need to improve communication to tell more information, I have the right, but they tell me limited information, like I'm the 'second class' citizen but I want more information"
- "Never had interpreters, just writing, concerns, what I think best for treatments, I asked questions, yes or no they tell me limited information, not a lot. More depth over medical

situations, I asked for more information to tell me, what it's meant, how it affects, how to improve, what is the plans in long term, things need to asked but never happened"

- "Freeman hospital never mentioned to me about diabetes"
- "End of care staff need to be more deaf aware for the family as well. My mother and son felt excluded – our family pulled together to help them understand what was happening"

These responses illustrate issues not only around communication but access to information about how best to care for the patient, if the wife was unaware of diabetes how could she ensure that it was managed? The need to communicate quickly often overrides the person's right to be next of kin and involved in the decisions. This is highlighted the examples above - his mother in law was contacted to relay information about his mother or having to make a decision about life changing treatment without an interpreters and then asked again a week later, without an interpreter. The fact that the conversation was repeated a week later meant that an interpreter could have been booked – if someone had thought about it.

> "A discussion took place to advise that all treatment should be withdrawn from my father to alleviate the pain and suffering. My daughter had to 'interpret' this message to her grandmother."

It may be important to note that the person who felt 'very' involved in the decisions about their partner is hard of hearing and therefore easier to communicate with.

Did you as their carer, receive the right support?
60% of respondents felt that they did receive the right support, but what is the 'right' support?

"I have no right to support given …" This was the reply from a man who had been looking after his hearing partner who had dementia and heart problems. He was asleep and not aware when his partner fell and banged on the wall for attention. His partner had previously refused equipment that may have helped - an alert buzzer. He received no formal support during the several years he cared for his partner.

"I had the daughter role and the professional interpreter role."

"Nothing, informed me nothing, never asked me 'would like to offer you … or arrange support?' never mentioned nothing. I think nothing about this and just normal carry on, not mentioned or bring up to me nothing."

One woman had received counselling when her husband was received treatment at Walkergate Hospital. On the day her husband died she asked a neighbour to phone her GP as she was worried about her husband's health. She was sent a fax from the GP surgery saying that the doctor would visit that afternoon. She went to check on her husband and realised he had died, she then had to approach a stranger to phone 999.

How could this have been improved?

"A lot of them talked to my partner's son because he is hearing …... But why don't they come to me directly?"

"I would like to get the 'picture' of what happens in the long term plans, what will happen, what to do, like what happens after she dies then what to do? If illness serious, what to do? Link to that I would like to plan long term and get information I wish."

The culture of acceptance is massive factor in D/deaf communities, for example "Only lip-reading, never got an interpreter, my fault." BSL users are not strong in asserting their rights or informing agencies of problems or concerns because they can't – without interpreters they cannot let people know how they are feeling. One D/deaf person said that when they leave the ward the nursing staff ask if everything is ok, put their thumbs up, "how am I supposed to tell them anything, they can't sign".

Did you receive the right support after they died?

No-one felt that they could identify yes or no to this question.

In the comments one person describes how his step son and his partner's ex-wife and her husband help sort out the 'funeral and wills and things'.

"but I can't use the phone, look on the internet how to find information, emails etc. Email seems hard and being ignored as phone calls quick. Phone easy and straight away accept information and sort out. Email is ignored, I have noticed."

"I need to know how it works to solve the problem, if I don't know what to do I am stuck."

"doctor talked too quick I didn't understand her"

"A lot of people talked around and I was lost, said nothing." "The coroner and my son talked, both knew well. I was in the middle, couldn't follow."

3 years ago support to a BSL user would have been a role for a Social Worker, helping them cope with the death of a loved one, understanding what needs to be done, informing the right people, arranging the funeral and helping with the administration of the estate. If the deaf person does not have family support the potential for abuse and deception is high, recently one BSL user in North Shields was recently charged an extortionate amount for a funeral, unaware of options and what she was purchasing.

There is also a danger that the family members are disempowering carers by making decisions on behalf of BSL users, patients or bereaved carers, without checking the understanding or needs of the individual. The lack of accessible information continues this disempowerment and total reliance on hearing people.

GENERAL FEEDBACK

This section looks at the 31 replies and how they feel personally about end of life issues.

The first question was only to the 26 people who have no experience of end of life care and they were asked if they were aware of end of life services. 58% of respondents were not aware of services. As stated earlier in this report some BSL users can believe that they are aware or informed but looking at the replies from the 42% of people who that they were aware of services it is clear that there is some lack of knowledge and understanding. The responses from the hard of hearing people show a higher level of understanding.

Where is the best place to die?

There was a very clear difference in the thoughts of the BSL and the hard of hearing respondents

72% of the BSL user replies identified the home as the place they wanted to die, their 2nd choice was a Hospice 22% and a 5% didn't mind and 5% a Nursing Home. The HoH people replies were reversed with 75% identifying a hospice and 12.5% don't mind and at Home.

The explanations identified key issues of isolation and communication issues as major factors. In fact throughout the replies, communication, lack of interpreters or BSL using staff was a consistent theme and concern. Anecdotally several relayed stories of people they know having difficulties

- "She was so alone and not able to communicate with her Deaf community"
- "Don't want to be the only one deaf isolated in care"

- “All the nurses at the hospital, and the workers, I never saw same person, different staff, no chance really to them to learn sign language because of staff turnover.”

When contemplating the end of their life and the plans one person said that they needed to meet with funeral director, they were asked if they would need an interpreter. The reply was “No I can talk” the deaf person is oral – they can speak and make themselves understood by hearing people however what about his needs to be understand the replies? The lack of availability of interpreters or services to assist in these circumstances has led to a number of BSL users resigned to ‘making do’ and not fully understanding what is happening and what their choices are.

Have you had a discussion with anyone about your wishes?

HoH yes 50% no 50% BSL yes 28% no 72%

What were the wishes?

In most replies this was because they held strong views that they wanted to be upheld when they died, such as the right to refuse medical treatment or that they want (or don’t want) to die at home. Communication, specifically the ability to communicate using BSL was a factor and some said they would be happy to use a nursing home if they had staff who could sign to a good level.

Why have you not discussed your wishes?

Most felt that there was enough time in the future or that they were too young to worry about this. It was never mentioned or being given the opportunity, or permission, to talk about the subject.

“Expect to discuss it when a terminal illness has been diagnosed.”
“I feel I am too young to worry about this, but I do wonder about this. However, I don't feel comfortable discussing this with another person, as it's quite a sensitive issue and they may not want to discuss it.”

Do you have any wishes?

Even though they had not expressed them to anyone many respondents did have very clear wishes and at least one person realised that they may need to address this topic with their next of kin.

- No idea but would like to see options
- To die peacefully around my family if it is possible
- don't want communication problems
- my religious beliefs are followed

Do you have any particular end of life needs due to your culture or identity?
61% of BSL users stated that they did have particular needs as opposed to 20% of HoH people who responded in the affirmative. This is to be expected as BSL users have a different culture, and perhaps more importantly, a different language. With the exception of one reply, who referenced religious needs, BSL users have noted the necessity for their communication needs to be met.

Fundamentally the replies are unified in the request for respect - for communication needs, for their sexuality and for their religion.

Any Comments?
"I would expect the NHS to provide training to interpreters about end of life care and then book these specialist interpreters only."

"There need be homes for the deaf in north east - too many elderly are being left in care home with no communication and their health deteriorated rapidly! It's hard enough to put hearing people into care home and it would be 10x harder for deaf people due lack of communication / understanding of their culture and their needs aren't being met they will end up very isolated and it affects their mental health wellbeing. Where's their equality access to the service?? "

"Deaf people cannot have their family ring them. If this is an issue an alternative could be video calls to their families."

"Teach communication and how to improve confidence etc. It's good, need deaf awareness all over really. Don't want (Deaf patients) to become isolated,"

"I need to prepare for my future, I never thought about this."

Additional Information

Prior to interviews we identified that we were asking people very sensitive questions and would potentially raise concerns or feelings of loss for example. In preparation for this we approached agencies and services in the Newcastle/Gateshead area who provide emotional support and asked them how a person who use BSL would ask for help from their services. These were:

- Talking Matters Northumberland,
- Sunderland Psychological Wellbeing Service
- Talking Helps Newcastle.

- Samaritans
- Cruse

The name 'Talking therapies' creates an immediate barrier for BSL users – who generally do not relate to the word 'talking'. The majority of these organisations take referrals by telephone or email. One organisation had telephone only and when asked what a deaf BSL user would do they suggested that the client could ask a friend or family member to contact them.

There is one organisation who specialise in support to BSL users with low level mental health needs, run by the organisation Sign Health, Healthy Minds is delivered by people who can sign. When questioned about access to this service we received the following reply:

> As the CCG already commissions many bereavement/counselling and support organisations we wouldn't be in a position to pay for patients to access Sign Health. We understand that Sign Health provide support for people who sign, however, the contracts we have in place require these organisations to support patients who have additional needs.
>
> If you do identify someone through the engagement that needs extra support, the advice would be for them to contact their GP and ask to be referred to bereavement/counselling services. The GP can then advise, as part of the referral that the patient has additional communication needs.

Our research shows that being able to ask the GP for help will depends upon whether they have booked an interpreter.

As a result of this preliminary work we have started discussions with several statutory and voluntary organisations with regard to accessibility for BSL users. A further benefit is that through the process of this work we have had feedback from BSL users and Interpreters that they were very grateful we had raised this topic, they had never thought and never had opportunity to raise it. That they 'didn't think about me or family needs'. They said that the discussion was very helpful and they were going away to talk to family.

RESPONSES

Black = BSL User Green = Hard of Hearing Red = Hearing Child of Deaf Adults

People with end of life care experience in the last 2 years

1 Have you cared for someone who has received end of life care within the last two years?

Yes	5	No	0

3 BSL users – one caring/cared for husband who was deaf, partner who was hearing and mother who is hearing.

1 Hard of Hearing person cared for wife who was hearing

1 Hearing CODA caring for parents both deaf

Has this person died?

Yes	4	No	1

2 What was your relationship with them?

Partner Wife Husband Mother Father

3 How long they were receiving palliative (end of life) care before they died?

2 years before died May 2016

2 days

1 is still alive and has been receiving palliative care for over 2 years.

6-8 Weeks

4 Do you feel they received the support they needed?

All 5 respondents felt that the person they were caring for did receive the support they needed.

a. Please explain why you think that?

"Well first time maybe two years ago he fell over a bag - to the hospital because his warfarin was too high because he lost lot of blood made his warfarin high so keep him in RVI then transferred to Freeman Hospital keep him in for 2-3 days until finally his warfarin blood back low then came home. After that he was alright but still not 100% and 2 years ago he started to fall lots. , he fell, I saw he have weak legs when he fell. So know what happened, phoned ambulance, neighbours helped clean my partner up.

Back and forward to the hospitals when he kept falling, then he got Dementia. When he started Dementia, I told doctor really he have dementia, the doctor said right will sort out with the General Hospital Dementia Ward, will get questioned there. When talked to my partner, he said 'I have no dementia no!' he really have, they gave him tablets. He won't listen and in a bad mood and after a while get worse fall, diarrhoea, hard work.

Then his heart started getting weak, moved to RVI hospital for one day and his blood was too high warfarin, back to Freeman Hospital and stayed ward 19 for Dementia ward, carry on and his heart get weaker and transferred to ward 37 serious ward. Back to ward 19, but getting worse and worse, Yes most nurses, staff work there look after everything him, feed him, and give tablets and things."

"Very good support from GP and nurse"

"Really 2001 from started in his armpit non-Hodgkin's lymphoma. Then 2007 back and forward from hospitals, last minutes (emergency admission) in hospital, no time for BSL interpreters. Next few months go to doctors and get sick note to off work, he went to the doctor again but they gave him nothing, just painkillers for his back. Then still frustration and in August, he was like to go mad himself and couldn't sleep in the night. Stayed awake through the night, then other way around he sleep through the day. So I was puzzled. Doctor sent him to x-ray in RVI and they said nothing there, we were puzzled and said it was impossible.

So then it was starting to get worse and worse, he getting more frustrated and get angry himself. I told him what can I do? He got problems with his legs, can't walk, and affected him. So I went to next door, Sandra she work as nurse for cancer in Freeman Hospital, asked her to do me a favour to come and have a look at my husband as he was not very good, it was at 12 o'clock at night. She came around and talked with my husband, he replied 'I want to go to the hospital'. So Sandra rang for an ambulance and it arrived quickly. They asked my husband if he can stay at home until the next morning, he replied 'no I want to go to the hospital' but it was Sunday and no doctors available.

So they took him to Newcastle General Hospital about 1 o'clock in the morning. Wide awake through the night, but can't do anything until in the morning. Then the nurse said you have to be transferred to RVI, so we waited and waited. Got in the ambulance and gone over to RVI Leazes Wing Ward 40. Put my husband on the wheelchair to Victoria Wing for MRI scan.

Then a nurse came in and said you have to be transfer to General Hospital. Again oh dear! So waited for the ambulance to go back to General hospital and got across to there and into Ward 32 or 33. Special Spine Ward, for injuries like head injuries in car crash. No interpreter nothing, just me and 5 doctors around my husband' bed. I said what I do as I'm Deaf? So the doctor said one is anaesthetist, one and each other one is something like professional operation etc., he wrote down on a bit of paper and I was over the head (overwhelmed) don't know what it meant as hard words so I signed what time for the operation? He was easy to lip-read – 9 o'clock at night. We were there around 5pm in the afternoon, so I texted to my son then he came.

I go downstairs for something to eat as hungry. When I came back up, I was shocked he wasn't there and the bed gone, no one told me where he is, it was 7 o' clock he was missing. So I tried to find the nurse, there was no one telling me where my husband is. So my son and I walked to home and didn't say one word nothing. Then came back the next morning, my husband laid on the bed, I asked him if he's alright? He nodded yes. He stayed in that ward for 2 months because ward 34/33 was the spine ward then he moved to cancer ward, easier for radiotherapy downstairs.

Then 2 years ago he was diagnosed with Diabetes. My husband had counselling at RVI with interpreter, for him and me problems as he had a lot of emotion through him. So he talked to the counsellor first, then swapped with me and I met the counsellor."

"From Gateshead Council, arranged through Social Services, agreed to register mentally incapable, means a proper organised service to look after and support what she needs. Very good support, social worker very good to me. Organised things and recommended what best for her future and provide interpreters. I have a right to access to the information that I need, good service. From social services, I have a lot of enquiries what best for her future and agreed to put her in the care home which was best for her, can't stay at home 24 hours impossible. **She had been having accidents, not fair and too much of mess, hard work**. Tried to arrange nurses, home visits to support her, she refused, some did happen but she want to be independent. Told her need more care, she refused and she's stubborn. Really very hard, been tried to persuaded her to go into a care home, she declined and said "give me time to think about it". So I leave her can't force her. But her talking now deteriorated, struggling and her brain shut down couldn't bring out words out of her mouth, stuck. I can see she tried to say something but gave up. Awful."

"With regard to my family circumstances, my Father and Mother and son are all deaf and BSL users. My daughter and I are both hearing. The doctors and nursing staff tried their best. However without the support of the Interpreting service and the Interpreter who had worked with my father for over 20 years I dread to think how much more difficult this would have been. It meant that **either my daughter or I needed to be present at all visits to facilitate communication and to try to make sure that my Father's needs were being met.**

However there was one occasion that we couldn't be there. When I went to pick my Mother up she was clearly distressed and said that a Chaplain was there in Dad's room she took this as an indication that he was going to die very soon. This was not the case and really upset the family due to lack of communication. When Dad was transferred to 'end of life' care Mam should have been his next of kin but this proved problematic. During a visit I encountered Health Care

Assistants shouting at him. I explained that he is profoundly Deaf they were apparently told that he was **Hard of Hearing.** A discussion took place to advise that all treatment should be withdrawn to alleviate the pain and suffering. My **daughter had to 'interpret' this message to her grandmother.”**

b. How could this have been improved?

Nurse or Doctor never say will book interpreter, so not expected, I thought few more days go on. Some know I am Deaf so they know to let me know and some will come help me, could help me to get an interpreter if the nurse know where to get an interpreter will and tell me ‘will get an interpreter for you’. But I can lip-read. How could be improved? **I don’t think can improved anything but I need some interpreter** in there hospital for emergency, that is the only thing I want to improve.”

“No. He doesn’t want anybody, only prefer me. Hard work though. I bathed him, made cup of teas, fed him, everything for him, no one else come, he doesn’t want them.”

“Other agencies **used phone to contact us**. I am hard of hearing and this was difficult”

“**It was difficult to communicate** so I asked my mother to repeat, lip-reading impossible to understand, her teeth is broken so I couldn’t follow. Communication support provided from Care Home, they booked BSL interpreters, provide interpreters from Northern Sign and good service. A lot of support, arranged everything and sort out smoothly. Very good contacting me a lot because I am the ‘next of kin’ important. Texted and informed me about my mother when have an accident, falls, something happened in bed, for example, ill caught chest infection and sent to hospital, informing me all the time very good. Doctors visited, petty cash need more money, and other things like that, very good contacted me and informed me.”

“The staff although they tried their best some of them admitted that they really struggled with caring for my father. The Chaplaincy service need some awareness and the distress that is caused by lack of communication. Any ward rounds or discussions should be done with a qualified interpreter present and an interpreter who is known with the patient and family as many interpreter booking agencies will not consider this vital service during a very difficult time”

5 How well the different did services work together?

“Yes, but not emotional help, like a lot of them come and help e.g. do you want a wheelchair? Stairs? Thing like panic neck button but he won’t use the button. Things provided, toilet and everything all helpful. Now when he gone all gone.”

"g.p. and district nurse worked well together, other agencies very much on outside"

"We have a chair stair lift from Occupational Therapist from Freeman Hospital, very good for him easy up and down. Wet room for him, he doesn't like showers because hurting his back, good handy for him. Loan equipment – bed, chair, toilet. Occupational Therapist come and training him walking, hoping he could improve, but never improved. **Newcastle social worker, had a lot from her but she left because of the cuts**".

"She paid for help in her home, when mother fall I contact them they came and special equipment lifted her up as can break back so carefully support when lifting, 2 people staff must support. Yes the service good give equipment like easy access for her, lift up from chair, have special toilet seat. But mother refused, would help her to go to the toilet but they provide nappies but problems in the end so had enough and better to be in a care home because more accessible service and support better for her 24 hours care. It was not possible for me to look after her at home. I only visit her twice a week that's all, Deaf Awareness well **no deaf patients there, I am the only one Deaf.** If any problems, just write down and show, emails and texts. Most of the time not much, only when serious happened to my mother they inform me. Arranged to take her home from family events like Christmas, I inform them what happens. Just briefly. Nothing bad. Very good service. Queen Elizabeth Hospital 2 years ago in Elderly patients department

I complained brought up in hospital over bad attitude, I told them I am the next of kin so contact me but **they contacted like my wife's mother so I told them no it's me you need to tell me direct, not her**. They were unsure, I said it's me important I need the information so I was not happy with the hospital. Told them to text me please, they said no so I challenged by complained to PALS, sort out and solved the problem they investigate and they changed to contact me directly. Some staff couldn't be bothered, busy looking after patients so it's happened please let me know. But now last few years contacted me regularly so been happened back to hospital and forth. Really awful times.

Must be 2 years ago, as I remembered my brother-in-law visited, I can see the hospital staff want to pass on information to my sister, I said no so I straightaway writing to them (that I am the next of kin) they realised. I said me information not yours, everything what going on must be writing, the nurse accepted not them. They backed down.

Been good support from the psychologist, checked IQ memory information test, been contacted me said its good then 3 months later drop dramatically**, they kept informing me with information that's good. I don't feel left out,** I have the right to access to information report of what been happened. Hospital and care home contacting me, also the social worker in the early days then no longer with social worker later as my mother gone into a care home. Then more focus on care home, no social worker anymore."

"A hospice stay was never mentioned. As a BSL Interpreter I have worked with terminally ill deaf people and have no knowledge of any mention of hospice, ever. I would strongly suspect that the majority of deaf people will not be aware of palliative or hospice care therefore a greater understanding and awareness of this by staff is paramount

6 Do you think that they were treated with dignity and respect?

Yes	4	No	**1**

a. Please explain why?

"Yes Hospital do very well"

"Treated as normal human being"

"Happy with General hospital, fantastic, but he was not happy with Walkergate Park, Not going to the dining room, we stayed in his room it was quiet. Because in the dining room my husband see the others like someone who can't lift a fork and upset him. My husband **was the only one deaf there.** Some ward rooms, people had accidents, one boy and one woman had her legs cut. They all had to have rehab it was difficult."

"Care home yes really good treating us, can't force my mother it's her choice, choose to decide, like for example, I have told the manager my mum need new glasses and teeth sort out, can see my mother refused so they have to respect her and leave it. Her choice, can't force her. **I asked for treatments like podiatry, haircut, clothes for her**. Problems with clothes mixed with others and lost, so complained, clothes lost asked them to put her name and room number on the label, they said alright."

"The staff were not able to communicate with my dad or his wife therefore if the interpreter, my daughter or I were not present then **only his basic needs were being met so how could he be treat with dignity and respect he couldn't communicate his needs**"

b. How could this be improved? How can be better?

"No bad experiences, just natural, not hate. Just want someone there like interpreter that all."

- Specialist BSL Interpreting services

- Ward rounds/discussions taking place when an interpreter is present
- Deaf awareness on the wards
- Accepting that a deaf person has the right to be next of kin
- Contact through Text messaging

7 How involved were they in decisions about their care?

"I don't know because dementia he can't remember anything. No idea as couldn't see him in general hospital, I only see him when visits."

"Good the patient was not deaf. As a deaf carer, I was treated well, and with consideration"

"Dementia treatment is not easy to cure, increasing number of people have dementia, I have seen in care home, many of them have dementia, they don't talk and just stare. Really bad, they (care home) are aware of the situation and try to talk and encourage them. They can't one-to-one all the time, too many of them and staff running around. All the staff are aware of the situation, so just leave it. Not easy."

"He wasn't, because he didn't understand, towards the end he didn't understand. He started biting staff and getting frustrated. I had to take time off work and **plan my hospital visits around meals to make sure he could communicate what he wanted to eat.**

8 Do you feel they received the appropriate support around their communication needs?

Yes 1 No **1**

a. Please explain your answer.

"no interpreter needed"

"**No BSL interpreters in the hospitals, only lip-read. I nodded sometimes** but realised I had to push myself to move forward, I had to look after myself. After discharged, he have regular check-up for every 3 months with a BSL interpreter in RVI then moved to Freeman Hospital NCCC (Northern Centre for Cancer Care)"

"(Mother is hearing) Not very good I can't, I don't understand at all, lip-reading no good at all. Lip-reading, her teeth is gone. We tried fingerspelling, can do some alright but sometimes she was stuck on fingerspelling as her brain shut down, struggling but can't. Same my wife (Deaf) when she visited but can't communicate with her because of her teeth, can't follow. When I try she understand I have to repeat and repeat but I talk about what? She became disconnected.

Meeting with social service last year they mentioned booking interpreter, I thought it would be nice why not, booked say for one hour but 5 minutes my mother forget can't talk more, she may forget or don't know. Long term memory she can talk she remembers, she telling me it's hard, **she telling less and less to me, most of the time I tell her but her response is not much**."

"No, not without us being there to help them understand him"

b. How could communication have improved?

"I had difficulty with some phone calls, and also hearing the door bell, when workers called."

"Lucky I hold 3 phone numbers of BSL interpreter we like, one for his background saving repeating all over again, we want the same interpreter know all his background."

"Northern Sign, really through care home, because not under social services, private company, I know one of the interpreters his family live there (care home) so I know happy to contact for information to provide me to arrange an interpreter I'm sure one hour once a month. Because every week, no good as only few minutes and talk about what? Not enough news, know it's hard, not easy. **Social worker for old age, as social worker for Deaf finished**. Interpreters should be available in emergencies, should be but need to find someone on 'stand by' through the day. Through the night interpreters are available but through the day is a question mark. Depends on which interpreter have cancellation, or two interpreters working together one can come to me (in an emergency) something like that.

"Deaf awareness and understanding of the need for specialist interpreters."

9 Do you feel that their cultural needs were met?

Yes	3	No	**2**

a. Please explain your answer

"He's Protestant. I think when I was not there, my partner said been a priest come and visited, talked before I came to visit him. What they talked about I don't know."

"No special needs"

"That why funeral director, no priest, Humanist funeral."

"No, not really. No cultural needs she have."

"Nor mother or my sons (*cultural needs*), on the ward they seemed to panic and didn't know how to cope with him and his deafness"

b. How could have improved?

"Deaf awareness"

10 Did they have a preference about where they would like to die?

Yes 1 No 3

11 Did they die where they want to be?

Yes **2** No **1**

a. If not, was there a reason behind this?

"Never said much about death, but he said 'If I die abroad rather cremated there, save bringing his body back. Other that he know want cremated. "

"No never mentioned, he like to be at home. Want cremated. Why? He love to be at home, watch TV."

"Never mentioned to me, never. Never say anything to my sister, never mentioned to me, any word never nothing. Difficult question, I don't know, could happen in hospital or care home, nobody know, I don't know. **She hate hospital, I know she wants to go home, she get annoyed**. I said treatment need to be until finished then she can get discharged. She moaned. Care home ok, really preference number one her own house, lived too long. Very hard for her to change lifestyle, more quiet, drowsy sleep, communication no good. Sad. Not like as 20-30 years ago she was active, walking around and exercise. Then when mild stroke happened, changed her life, seemed quieter same as other older people I've seen."

12 Were they made comfortable in the place where they died?

Yes **1** No **0**

a. Please explain your answer

"I don't know if he was comfortable, but I think he rather want to be at home."

"Nurse readily available, by phone"

"Never mentioned, just happened peaceful at home. Peace in bed. "
This is the description of what happened:
"Later suddenly, My husband' mouth was trembling and moving a lot, he rubbed his arms and his tummy so I thought he only wanted the toilet he never said anything and went upstairs, but sounds were a bit funny so I went up and saw him in bed. So I tapped him on the arm, his arm was freezing, asked him if was ok, he said alright so I went into the shower, then I tapped him again on the arm, his left arm was very cold, I asked if he's alright, he said oh yes. So I told him to have a rest for one hour. I went downstairs, I became not sure, so I checked him again and he was asleep, asked him if he was alright, he replied 'want doctor'. So I became concerned and how to get a doctor? What can I do as can't phone?

b. How could this have been improved?

"I wanted to be there. Because when I'm there he know I'm there and his son will be there, want to keep company."

At least 2 of the respondents said that their partner had said that they only wanted them to care for them. It is not clear if they were offered support (or training) to provide this physically and emotionally difficult task. j

13 How involved were you in decisions about their care?

"One nurse said 'are you family?' I said 'no just partner', she said 'you are family, partner same as family just go on as family, if not I will separate but you are family'. **Most of the time I was in the decisions**, my partner's son sit back waiting for me to say things what they want or not, my decisions. My partner's son sit back, when I said I agree with doctors, he agreed.

He was on ward 37 serious ward (Freeman), then next day fine, started eating sandwich I was puzzled what wrong with him? Back to ward 19, but getting worse and worse. Before that, the doctor knew he had a weak heart, said 'do you want to switch off his defibrillator?' I was unsure and said no not yet. One week later, other doctor came in and said he still have a very weak heart do you want to switch off the defibrillator?' I was unsure I rather someone tell me, his son was quiet, I looked at son said nothing. Alright I decided yes, son said alright yes. I know my partner don't want to be 'cabbage' don't want to be still, want to keep moving on, so I have to think for my partner, said have to switch off so he's gone.

His son and daughter came. I didn't expect he will die that night or anytime soon. I thought plenty time maybe one week or more. His son and daughter left, I stayed an extra hour because I

never before had an extra hour visiting, so I stayed and he was still not good so I kissed him bye after 9pm I went. In the morning I got up, his son texted me said Dad died at 3 o'clock morning. He texted me about 8 o'clock in the morning so I rushed to the hospital, he already died and cleaned up finished. So I stayed and doctor came in quick.
At any stage did you have a BSL interpreter or ask for one? No I haven't asked for an interpreter, I know because interpreters can't come emergency, I know most of them always work.

"very involved"

"Never mentioned to me, only social worker arranged care home and offer treatments, **hospital never mentioned to me nothing.** I've asked the staff ward sister team, I asked what treatments, arrange what, what best for her etc. I asked and asked. Been regularly writing, emails etc. Been writing to give information about what I will do, can do, monitoring care etc. up to the doctor to decide, I don't see the doctor. Wrong time, wrong place. What plans? Inform me when?, carry on tablets or plans in the future, etc., nothing.

Never had interpreters, just writing, concerns, what I think best for treatments, I asked questions, yes or no they tell me limited information, not a lot. More depth over medical situations, I asked for more information to tell me, what it's meant, how it affects, how to improve, what is the plans in long term, things need to asked but never happened"

"Freeman **hospital never mentioned to me about diabetes**, what level is good, then I found out from GP later my husband got Diabetes, I was puzzled. In Walkergate hospital, there were doctors around my husband, nurses, social worker (Sue who can sign) and doctors over my husband he wanted to go home, he couldn't stand the hospital. They asked me if I can look after my husband, I said yes I can manage look after him. But need something for him like equipment like bed, chair lift etc. "

"End of care staff need to be more deaf aware for the family as well. **My mother and son felt excluded – our family pulled together to help them understand what was happening** and the hospital took advantage"

14 Did you as their carer, receive the right support before they died?

Yes	3	No	**0**

a. Please explain your answer

“**I have no right to support given** but I needed someone to support me like nurse, just my partner’s son come, if we needed any help.

Next door neighbour, he helped when I was heavy sleep in bed, my partner fall in passageway and banging the wall with his walking stick, I couldn’t hear as my hearing aids were off. The people next door watching TV heard the banging and came around to the front door, tried knocking, I was still heavy asleep. I felt I needed to go to the toilet and saw my partner was not there, I got up and found my partner lying in the passageway. My partner said ‘downstairs someone at the door’. I said ‘who?’ I opened and realised it was next door and came up I couldn’t lift him up he was too heavy because he not helping to get up, he was just slumped. So next door Liz helped lift him up to bed but after that he got worse and worse.”

“I don’t know! A lot of interpreting had to be done, **I had the daughter role and the professional interpreter role.** During that time I was struggling with work because I couldn’t let deaf people down and understanding and helping my father.”

“Nurses were very sensitive to my feelings”

“Nothing, informed me nothing, never asked me ‘would like to offer you … or arrange support?’ never mentioned nothing. **I think nothing about this and just normal carry on, not mentioned or bring up to me nothing.**”

“Walkergate Park Hospital arranged counselling, for me because of my husbands’ behaviour, he was very bad tempered, scared me awful, really ungrateful with me in Walkergate Park as he expected to go home, I said “no you need to stay for rehab for 4 months, he wasn’t happy. He was horrible to me, so I got counselling.”

The day her husband died he was in bed and ill …..

“I saw out of the window, I saw neighbour David and his car, so I went down to him and left my husband, I didn’t know how long died or live, I went up to the neighbour and said “my husband want to see the doctor” so he find a phone number and phoned the doctor in Saville Place. He was on the phone for long time, I said want the doctor to come out now, the neighbour said sorry busy that morning. The receptionist want me to talk on the phone, I said ‘Me? I’m Deaf! I can’t talk’. David said ‘she is deaf and not good talk, can’t hear’. The receptionist said ok and will send me a fax, I said need now! Come now! She said no sorry. When I got the fax, it read doctor will come around in the afternoon – I was shocked!

So I better walk up to see my husband, saw him and he is already dead! I tapped him and thought what to do?? David gone to work, but still texted him. Saw someone on the third house up the road, saw a woman putting in the bin, so I walked up to her and said hello, excuse me can you do me a favour? Can you help me, my husband have problems, I think he passed away. She came with me to see my husband, she phoned 999. I never thought of press 999, my mind was blank."

b. How could this have been improved?

"**A lot of them talked to my partner's son because he is hearing,** when something to tell they not come to me, they come to my partner's son and talked, I asked 'what?' he said wait and when they go he tell me, I asked 'what wrong'? **But why don't they come to me directly?** Maybe if say what time doctor want to see you then book an interpreter".

"It might have been nice to have some-one just for me"

"I would like to get the 'picture' of what happens in the long term plans, what will happen, what to do, like what happens after she dies then what to do? If illness serious, what to do? Link to that I would like to plan long term and get information I wish. I haven't received and read nothing, from care home nothing. No information. "

16 Did you receive the right support after they died?

Yes 0 No 0

a. Please explain your answer

b. How could this have been improved?

"My partner's son did most of the work, organised things and my partner's ex-wife and her husband both do a lot of things for me, arranged everything funeral, and wills and things. Now a little bit cleared. Now I can manage myself, I don't need a lot of support now, because my partner's son there. Ex-wife's husband is good work with accounts, tax form and things for me. A lot of money and now waiting for probates that will be sorted and told wait need more time before give up the will."

"I don't know how it works, I know when my father passed away, my mother sort it out. I know the house already sold, I have to contact people to stop post, electric, gas, council tax, and other things have to stop. Finished that it's sorted out. Information from her solicitor, the will, they have information. I have power of attorney, already arranged. Talk about bereavement and things, how to contact the newspapers, have to inform her good colleagues from her old work. I think best my sister in Australia to inform our family, aunties, uncles and cousins to let them know. Need publicity in newspapers, like Evening Chronicle, funeral arrangements, how to pay funeral? I know it's expensive. I don't know everything about arranging funeral. Never used to it, same as everyone else get shocked when someone died and don't know how to do funeral, get support etc. **How to phone, but I can't use the phone, look on the internet how to find information, emails etc. Email seems hard and being ignored as phone calls quick. Phone easy and straight away accept information and sort out. Email is ignored, I have noticed.** Access for Deaf people become barriers and stuck. Like that happened, not easy to access to information. I will have to talk to the care home, to plan and prepare for what will happens and for support, how to arrange etc. **I need to know how it works to solve the problem, if I don't know what to do I am stuck**."

"Police came quick, a man and a woman, then a woman **doctor talked too quick I didn't understand her** so I asked the policeman what she said, it was a special machine for heart rhythm, he said she asked where is your husband? I pointed to upstairs, she went upstairs.

So the two police officers, the doctor went upstairs, the woman neighbour were there, then the first neighbour David came back to make sure. So the police asked if need a BSL interpreter, I have a phone number of the interpreter I always choose for my husband, for his regular appointments. Quickly that interpreter came, good. Then I explained what happened in the morning same story all the way through on that day. They asked questions like who is doing funeral? I got the Sun Life insurance papers and showed them, contacted with Co-op funeral director. They phone Co-op and the director came. Ooh a lot of people there.

Then my son phone (he lives in the south of England) my husband's sister and niece and they came to visit to see my husband. It was awful. A lot of people talked around and I was lost, said nothing.

Director said have to go back to RVI, because my husband died at home. So he phoned and Civic Centre coroner said Wednesday morning at 10am. With my son, he stayed at my house. Took my husband' body to RVI. Next morning, Civic Centre Coroner, we sat and said nothing one word. The coroner and my son talked, both knew well. **I was in the middle, couldn't follow**. My son said 'RVI been took a sample, a square off the arm or body, like a stamp, square taken out'. But the coroner need permission for post-mortem as wanted to know what was the cause of death. So I signed the paper then he went to RVI for the post-mortem by Thursday, he will let us know the results on Friday. But my son was too busy, working, no time and heard on the Saturday, confirmed he got acute myocardial, quick heart attack, just died with heart.

When husband died, 2 weeks later, received a letter from GP. The doctor want to see me at 10.30 in the morning. So I went over, nice doctor (no interpreter), hugged me and said very very sorry it happened this way, I know it's very hard for you to phone. Really really very sorry. She realised. The funeral went smooth, as had the life insurance so they sorted it out for me, with my son. So I have a lot of time now, better out with my friends. Only lip-reading, never got an interpreter, my fault."

17 Do you have any other comments about end of life care for patients and for carers?

"Fewer people involved the better. Any involvement needs to be incorporated with main care. **We had workers saying they would do things, then didn't**"

"**Especially the hospitals, need to improve communication to tell more information, I have the right, but they tell me limited information, like I'm the 'second class' citizen but I want more information.** I like to meet the doctors but really they are busy, hard to see them. The staff can't do anything to decide, stuck, 'have to ask the doctor, they know best'. So I feel helpless. Maybe worthwhile I contact the care home, plus the doctor, to arrange and can give me a report, I have the right to access the information what I need to know, what is the long terms, what is impact etc. My mother can't tell me, because of her dementia. So they can tell me, I will bring up with them soon as possible."

People with no end of life care experience

1. Are you aware of what services are termed as 'end of life care'?

Yes	11	No	15

a. What are they?

- Do they do things on video?
- Is it about communication and pain?
- I remember (person who was dying) their signing was reduced and I just left them.
- In my family – lots have died. All had expectations, they wanted to die suddenly and I get upset. The details… too hard.
- Macmillan nurses, Social services, Marie Curie.
- Palliative care befriending hospice respite care.
- Provide help for the patients who are going to die soon and support the people around the patients.
- Patient offered options of services, the environment and how they wish to end their life
- Hospital, Carers coming daily or 24hrs
- I'm assuming they can mean any range of health and social care services supporting those at the end of their life. That could range from hospice care to the support from local GPs, Macmillan nurses, pharmacies, meals on wheels and help with personal care.
- Hospice Bereavement Counselling

ALL RESPONDENTS

1 Thinking about yourself, when the time comes, where do you think would be the best place to die?

Where	Group B BSL	Group B HoH	Group C BSL	Group C HoH
At home	2		11	1
In a hospital				
In a hospice			4	6
In a care home				
In a nursing home			1	
Don't mind	1	1		1

Somewhere else **1** please say where…**South Africa**

Comments

Care home

“My grandmother lived on her own, she was lonely, no communication with staff there. I used to go to see her and she missed the deaf world. Two days before she died, she said she had had enough, she was lonely, isolated and when she died I got such a shock. **She was so alone and not able to communicate with her Deaf community** that was 17 years ago. She did not have the communication she needed.”

“Don’t trust care home, because sell the house to pay them, no. Rather at home, prefer. Or natural die at peace. ”

“Don’t want to be the **only one deaf isolated in care home** or they not bothered about me. Who to talk to me? No way.”

Death at home

“my uncle did and know that the nurses came in, I went in, but communication impossible, and it was hard to explain, I never forget that a few years ago.”

“**All the nurses at the hospital, and the workers, I never saw same person, different staff**, no chance really to them to learn sign language because of staff turnover.”

2 Have you ever discussed with someone your wishes regarding end of life care?

Yes **10 (hoh 4)** No **20 (hoh 4)**

a. **If yes, what are these wishes?**

- If I was diagnosed with a terminal illness or been seriously injured (where the quality of life have been robbed) I would rather to die than have too many people come and go and can’t communicate with me at all - I would feel I’ve been left with no dignity. I would rather choose to die peacefully in my own home - in an environment that I am comfortable with or even if there was a deaf residential home for elderly / illness / injuries where all staff are signed fully at minimum of level 2/3 to enable good communication between both parties.
- Not properly, will get talk with the funeral director, I have no life policy, and my partner didn’t let me have a life policy. I said should have. That why I have heavy tax after everything. Better will ask my partner’s son to try get me a life policy but I think I will go

myself to talk with the funeral director. *Would you need a BSL interpreter for this?* No I can talk.

- Offered little and lost ability to make a decision so very difficult could understand family moved to hospice but ignored lots in hospital
- I wish I would travel all the world and try new things.
- Have signed a living-will and my relatives know I a) want a D.N.R. b) my brain goes to Newcastle University Brain Tissue Resource plus Age UK. Funeral plan with H. Duckworth Funeral Service
- I want to die at home. And if not possible I will just shoot myself.
- I don't want to be kept alive
- home if practical for family
- Not hospital. If lose capacity refuse all treatment except pain relief. Written in living will so no one can argue.

b] If no, why have you not discussed your wishes?

- Unless its sudden death, **I consider there is time** to give family my personal wishes of what I want, and would be addressed when, or if, an illness couldn't be treated or improved.
- Expect to discuss it when a terminal illness has been diagnosed. **If I drop dead on the spot don't really care what happens next.**
- Not got around to it but probably should.
- Too young and I am a carer of Deaf family, not Deaf myself.
- My family think I am being morbid. However **I've told them I am on the donor Register** and expect them to let them use whatever organs are fit for use
- Just there is no one to discuss with!?
- **Too young to worry about this**.
- Because I don't know and my parents didn't talk me about life of end
- Because they never told to me.
- Because I am young and would not discuss about my wishes right now but I will be able to discuss my wishes when the time is possible for me.
- They are too old to worry as have enough on their plate.
- Never mentioned, never think about this. It not in my mind. I have noticed, 21st century culture changed, more like for my children, busy lives, ‘Can’t be bothered’ and concentrating on parties or their lives come first and ignore family. In my time, I do more care on my family, I have seen the change in society, no respect, and people become not bothered, put old people in care home and just relax. I have noticed the change in society become less loving, they concentrate on their own lives. Difficult

question, Deaf really hard send into care home, number one problem is communication breakdowns. Become stuck and decline quickly to finish, become depressed and isolated. I want to see a Deaf care home for Deaf people only but the problem is money/funding plans etc. but I would like to see that one day in the future set up. But I think all staff need Deaf Awareness training set up by the government. Like if the council won't set up a care home for Deaf people only because of the money, should provide Deaf Awareness training to all staff. Perhaps need to talk one day.

- Never think about it
- I hope that I'm too young for this at the moment
- Never got around to it as still under 30
- Haven't talked about anything, I never told my son not yet. But my son and his dad always hid from me, they talked to each other. I don't know what they talked about.
- I feel I am too young to worry about this, but I do wonder about this. However, I don't feel comfortable discussing this with another person, as it's quite a sensitive issue and they may not want to discuss it.
- **Find it difficult to talk about end of life**
- I have never really thought about death, and end section of my life. It is a sensitive topic indeed to talk with anyone, and I would say it is because I am still young but then people younger than me dies anyway.

3 Do you have any wishes? What are they?

- Depending on the illness, I would have peace of mind knowing that I could be cared for, if lucky enough to be offered a place in a Hospice. The holistic services, nursing staff and environment are simply the best way to end one's life.
- As little pain as possible - get it over as quickly as possible.
- I would like to be communicated to using Lip Speaker. I want to be cared for by people/professionals who are Deaf aware. I want to know what options I have and to be fully involved. I want people to use plain English and communicate with me as an equal I don't want anything discussed about me without me I expect that if I make a decisions about my care/treatment that they are respected and carried out. **I want to die with dignity and not alone**
- No idea but would like to see options
- Setting up wills, end of life care.
- I need bit support for communicate used BSL
- **To die peacefully around my family if it is possible**, to give someone in my family my will. If I have some illness I may want my family to support that charity in a memory of me.

- Do not resuscitate as **don't want communication problems** to stress my end of life. **There are no agency or carers use BSL, nor NHS or Macmillan nurse.**
- Never thought. Home, better than suffering in hospital etc. Awful, best peace in home. If on Life Machine, my brain is 'cabbage' what is the point living like that? Haven't brought up like that, haven't made a will, arranging funeral, end of life, and haven't thought about this. I don't want to be cremated, rather be buried, what is the point?
- Buried. If had accident **would not want machine switched off.**
- To not be in too much pain
- **BSL interpreter**, nurses that can communicate with me
- Yes I want to make sure that **my religious beliefs are followed** when I am dying.
- Not that I can think of.

4 Do you have any particular end of life needs due to your culture or identity?

Where	Group B BSL	Group B HoH	Group C BSL	Group C HoH
Yes	2		11	2
No	1		7	6

a. If yes, what are they?

- Lip speaker so far but may deteriorate- living will must be used
- I need someone who has sign language skills and to understand deaf culture.
- I am a Catholic and would like communication with a priest consideration of deafness
- I am a Catholic and would want to see a priest
- Yes I need a BSL interpreter. If I put into a care home or wherever, I might need a BSL interpreter if any problems. Other times, I can lip-read.
- Being gay I would simply like my family and friends (and me) to be treated with respect. Also being hard of hearing, I need staff to be able to understand how best to communicate with me and to be able to understand how my hearing aids and streaming aids work!
- I want to go home, to hospice/ hospital and receive treatment/health support or care by people who can sign or are Deaf aware
- used BSL for communicate
- a signer or to be there for a support
- my religion - have a funeral (Janazah) the next day or so in a mosque with prayers around family and close relatives also a prayer depending on the time (5 times a day prayers)
- BSL user. If in hospice with BSL also visual relaxation not music

- Signer in hospital. Hospice where people can sign + understand deaf culture. BSL and SSE. Visual support
- If any problem with my health, I need a BSL interpreter, a nurse, woman nurse, not man.
- Yes, I want to make sure my religious beliefs are followed (Islam). I also want to be aware of what is happening, if possible, via sign language interpreter or staff that can sign.
- I am deaf, so I would like to be somewhere where people can communicate with me properly, maybe a care home for deaf and Deaf people.

COMMENTS

NHS Hospitals don't have hospice 'End of Life' services offered to those who want and need holistic care. WHY?

There need be homes for the deaf in north east - too many elderly are being left in care home with no communication and their health deteriorated rapidly! It's hard enough to put hearing people into care home and it would be 10x harder for deaf people due lack of communication / understanding of their culture and their needs aren't being met they will end up very isolated and it affects their mental health wellbeing. Where's their equality access to the service??

I would expect there to be someone who is able to provide BSL communication for my family members. I would not like there to be communication with interpreters only. If the staff themselves could not be trained in BSL, **I would expect the NHS to provide training to interpreters about end of life care and then book these specialist interpreters only.** This is because interpreters can be quite professional and cold, due to the nature of their job. I would expect staff to have Deaf awareness training. I have heard stories of deaf people being treat as if they are aggressive and non-compliant in hospices/care homes due to feeling like no one can communication with them. Another important factor is visiting times. **Deaf people cannot have their family ring them. If this is an issue an alternative could be video calls to their families.** NHS could provide tablets to Deaf people in end of life care to help them speak to family.

I am glad Deaflink are carrying out this research. I only hope it does help towards making positive changes instead of being put to one side having ticked an NHS box on some audit

I would like died in South Africa because I grew up in South Africa and there is beautiful view

Current service not looking good for deaf BSL users, always struggle every day to be understood. Don't make end of life a problem for us too.

Teach communication and how to improve confidence etc. It’s good, need deaf awareness all over really. Don’t want (Deaf patients) to become isolated, and nothing to do then become decline quickly not fair. Families pay a lot money to care homes, they are not cheap, really expensive. A lot of people force to sell their home for sale, to pay a lot to care home and quickly money go down to finish. Awful and frustrating.

Never mentioned to my family as I am not yet old 80 or 90, not yet. Not looking into the future yet, never thought. I need to prepare for my future, I never thought about this.

PROFESSIONAL OBSERVATION

As part of the research we spoke to a number of interpreters who have experience of supporting BSL users through the 'End of Life' stage. We felt that this gave a different, and useful, perspective of patients and family's needs at the End of Life stage. These are some of the examples they identified – some very good working practices and some that raise some issues.

"I have, as an interpreter, had the unfortunate situation of conveying to many deaf people that they have a terminal illness or work with them as a result of them having a terminal illness. Reactions have varied considerably from hysterics, shock, non-reactive or dismissive to name a few. The support they receive I believe is influenced by this initial reaction. The health care professionals are so very reliant on us as interpreters to gauge how the patient acknowledges this information. I always ask to recap and reiterate what has just been said explaining and expanding on the options very explicitly. I do, without doubt, believe that **familiar** interpreters should be used during this time as it gives people reassurance and comfort that they know someone they can trust. Many deaf patients receive this information on their own, without family present or have no family.

Some examples:
About 5 years ago, an elderly deaf man, widower, living alone, unable to recover from broken arm, dementia but able to communicate and understand quite well. He gave up in a way but still looked forward to seeing people. He was put on the Liverpool Care Pathway as end of life care. He was told they could do no more for him and that he would die. He just shrugged his shoulders. It was horrid for him, he was basically starved and given no fluids until he died. Each time I attended at the request of nurses/doctors he asked for a drink as he so desperately wanted one. There was always a drink at the other side of the room which he could not reach (part of the plan). I could not deny him this drink. He asked every time. I explained to him each time. Family had agreed to the plan and they did most of communication with health care professionals. He had no control or decision making at the end of his life. It took several weeks for him to die. Hearing family with one other deaf member, **familiar** interpreters used occasionally.

Approximately 2 years ago. Elderly deaf woman, widow, living in supported housing. Fell and fractured hip. Very limited eyesight and early dementia. Her preferred Interpreter was present during initial admission and diagnosis. She was told, via interpreter, the options available. Her hearing family also present and they had very limited BSL skills. She decided not to accept surgery. She would therefore not recover. Had capacity to make that decision. Her condition deteriorated as did her mental state. Staff were very conscious about ensuring she understood everything as far as possible during her stay until her death. They called interpreters in almost on a daily basis but towards the end she was unable to communicate all. **But she was given the chance to**. She stated that she had had a good life and accepted her pending death.

Elderly man given terminal diagnosis and 18 month prognosis. GP very proactive in his long term care and clear that she would support him to die at home as he wished. This was decided very early on after his diagnosis. He was very informed with decisions about his care with GP, consultant and nurse specialist. Regular reviews of care. Always with **familiar** interpreters. Macmillan nurses involved later through his illness who offered excellent support and he accepted or declined treatments after considering the options available to him. His family very much involved also and became a family discussion most times with the final decision being his. He died peacefully at home after four and a half years and I believe had a very dignified end of life care because it was well planned, guided and he was kept informed of every single step along the way. Deaf family, involved with **familiar** interpreters throughout.

Elderly man, fell and was not able to recover. Early dementia, Parkinson's disease and other conditions that prevented him from recovery. Excellent communication with himself, family and hospital team. Very forthright discussions and realistic in expectations all discussed with him but he was limited in his ability to respond appropriately so family ultimately had to make many of the decisions. Treatment invariably withdrawn as no realistic chance of recovery. Deaf family, involved with preferred interpreters throughout.

Deaf woman, I attended of my own free will at the hospital where she was as no interpreters had been arranged even though she had been in hospital for over one week. She told me she had cancer but she said no more, only that her family did not want anyone to know. I felt it was taken completely out of her hands. She appeared very frightened. I sat with her for a while. I never saw her again. I have been told since that her family decided everything for her. Interpreters were rarely used during her illness, and that was decided by family when interpreters would attend, not her. Deaf family wrote messages to doctors and withheld info from her. She could not stand up to them.

RECOMMENDATIONS

End of life never easy, can't meet everyone's needs or be everything to everyone. However the experiences of D/deaf BSL users are that they have anxieties and concerns about what they are going to experience, based upon their knowledge of what has happened before to others such as isolation, needs ignored, dying lonely and no-one to speak to. This is a significant factor in their desire to die at home – where they will be supported and communicated with.

> *"Current service not looking good for deaf BSL users, always struggle every day to be understood. Don't make end of life a problem for us too."*

This research has identified the following key areas:

1 IDENTIFY THE AND INFORMATION AND COMMUNICATION NEEDS OF PATIENT AND FAMILY

1.1 **Implement accessible information standards** – Ask, Record, Flag, Share and take Action. If this was followed the majority of recommendations would be met.

1.2 **Consider Communication**. A GP asked a grieving widow to go to surgery to offer apology that they couldn't communicate with her when her husband was dying. GP did not book an interpreter.

1.3 **Take responsibility.** A hearing mother and deaf son, she has dementia and is struggling to understand him and he to understand her. Their contact is reduced and it is impacting on their relationship.

1.4 **Stop assuming.** If a BSL user says 'I can lip read' or 'I can speak' you still need to think about what they can hear, communication is a two way process.

1.5 **Check if the deaf person is in the loop?** Do not assume that the D/deaf patient is informed or has understood what is being said and done. Who's perspective is it?

2 USE A COMMUNICATION PROFESSIONAL

2.1 **Use Professional Qualified Interpreter** – many interpreter provider agencies use level 6 (and in some cases not even level 6). This is not a qualified interpreter, there is training beyond the academic level 6 qualification.

2.2 **Use a Preferred or familiar interpreter.** Not only will the BSL user be more comfortable and confident about the information being given but the interpreter will know if the BSL user is not following or understanding the conversation. They will clarify that both parties have the right information. They will respond in a professional manner when delivering difficult information.

2.3 **Good practice/Law or Common decency?** – When delivering bad news and considering withdrawal of treatment this should never be delivered by family members acting as interpreters.

2.4 **Better systems to book interpreters.** Whether staff don't book them or the agencies can't provide them is unclear but the majority of interpreters are 'on call' for emergencies. Are the booking agencies available 24/07? What happens if the 'preferred interpreter' is not on that agencies books. In cases of emergency BSL users should be given the opportunity to book their interpreter and paid by the relevant organisation.

3 SOCIAL AND CULTURAL NEEDS

3.1 **It's not just about the medicine**. A person's access to health and social care services shouldn't be dependent upon hearing capacity. There are assumptions of level of understanding and an ignorance of deaf culture. On respondent said that their partner had a lymphoma in 2001 and later developed cancer in 2007, is terminology appropriate. There is a clear need for deaf awareness treatment throughout.

3.2 **Feedback.** Deaf people have never said that they've had problems? No complaints? How do you know without an impartial interpreter who will enable communication? Deaf people accommodating "I don't expect support", "I didn't think to ask". Some will say they know, but they don't and are too embarrassed to ask to have it explained. Time needs to be given to check understanding.

3.3 **Contact/Communication methods.** BSL users can't use the telephone. Many prefer using text as a high level of written English is not required. There are some things that are available that might help in an emergency - they can register their mobile for 999 calls to be accepted from their mobile. Next Generation Text (replacing speech to text) can be used but a lot of BSL users, especially the older ones are unaware of these services – they need to be advertised and promoted. Providing information in plain English. How can a BSL carer or patient can communicate with the next of kin during a hospital stay should be considered.

4 SUPPORT FOR CARERS

4.1 **Take time to understand an individual's circumstances.** Do not make assumptions - about the person's ability or understanding. Many BSL users have indicated they want to die at home, because they can communicate in their language and not feel isolated. "He wants just me" it's difficult for a carer to refuse to provide support to the patient or to admit that they need help when they are hearing, deafness will add another barrier to open communication. Is the carer saying 'let me do it, only I know how to look after them' or are they frightened that the professionals don't know what they're doing?

4.2 **Communicate with the next of kin/carer appropriately** – involve and include the family and respect the next of kin, communicate with them, not the distant family members.

4.3 **Ensure all options are explored and understood** – are people clear about what's available? How – nobody books interpreters! The interpreter who has worked for many years with terminally ill deaf patients/families stated that they had never heard a hospice being discussed.

4.4 **Educate and inform.** Many BSL users said they didn't have enough information. Some of them described situations where some knowledge and understanding about what to do in an emergency and how to recognise that it is an emergency would have helped greatly. The deaf woman, when concerned about her husband, would have contacted 999 and not tried to get an appointment with her GP. What information about first aid/health issues if someone is a carer is in BSL?

5 BEREAVEMENT SUPPORT

5.1 **Specialist support service**. As described earlier BSL users can become reliant upon their hearing partner or children and when that person dies the deaf person can be very vulnerable. Sensory support team cuts have taken away the formal support that was once provided to a bereaved BSL user and now they have to rely on others and this has potential for abuse.

5.2 **Accessible emotional support.** Newcastle talking therapies, Cruse etc. cannot be accessed by BSL users. Not only because a person needs to phone for an appointment (or find a friendly hearing person you trust and want to divulge that you need this service to) but because BSL users do not know the service and do not trust it. This will take several years of working within the deaf communities and getting positive testimony/approval.

DIVERSITY MONITORING

Gender

Female	24	Male	7

Age:

Under 18	**1**	18 - 24	**6**	25 - 34	**3**
35 - 44	**5**	45 - 54	**3**	55 - 64	**4**
65 - 74	**4**	75 - 84	**5**		

Sexuality?

Lesbian	**2**	Bisexual	**2**	Straight	**23**
Gay	**1**	Prefer not to answer	**1**		

Ethnic background

British	**26**	Chinese	**0**
Irish	**1**	White and Black Caribbean	**0**
Central/Eastern European	**0**	White and Black African	**1**
Indian	**0**	Other British Pakistani	**1**
Pakistani	**0**	Caribbean	**0**
Bangladeshi	**2**	African	**0**

Do you have a Disability?

Yes	**27**	No	**4**

What is the first part of your postcode? e.g. NE2

NE3 NE9 NE2 (2) NE7 NE12 SR1
NE23 (3) NE6 (3) NE29 NE1 SK10 SR8
NE22 NE4 NE33

Blind/Visually impaired	2
Homeless	0
Person with a Learning Disability	0
From a Black or minority ethnic community	3