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'My Mum's Story'

A Deaf daughter discusses her Deaf mother's experience of dementia

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With a Foreword by:

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Abstract The following paper concerns culturally Deaf people, who are Sign Language users, and who develop dementia. A first person narrative account from a Deaf daughter of her Deaf mother's dementia ('My Mum's Story') is the main focus of the paper. It is preceded by a Foreword designed to equip the reader with the background to Sign Language and Deaf culture, in order better to contextualize the significance of dementia and its effects for this community. Both pieces, from different perspectives, focus on: the problematic nature of recognizing dementia amongst Deaf people; the paucity of appropriate diagnostic, care and support services; the different considerations for Deaf people approaching dementia as patient or carer; the challenges to service providers and researchers. The first person account was originally produced in BSL (British Sign Language) and translated for written publication purposes.

Keywords Deaf culture; deafness and dementia; sign language

Foreword

The following story is a first person account by a daughter about her mother's dementia. The story was signed to us in British Sign Language (BSL) because the author is, and her mother was, Deaf.

Deaf with a capital 'D' usually refers to Sign Language users; and deaf with a small 'd' is usually used to refer to people who have lost their hearing, or people who are deaf but use spoken language. British Sign Language is not a series of gestures, or a visual way to try to represent English. It is a totally separate language that is recognized by the British Government as being one of the natural languages of the UK. About 70,000 people in the UK use BSL as their preferred or only way of communicating

(<http://bda.org.uk/>). It has no written form. When stories are told, like the one the author shares of her mother's dementia, they are living history, captured on film. They are conversations without spoken words in which meaning is generated through the grammatically precise use of movement, handshape and facial expression within space (Sutton-Spence & Woll, 1999).

You will be reading the story in translation.¹ Like any translation it is a best attempt to reproduce the original meaning and it is a good one. However unlike translating between two written or two spoken languages there is something extra. One is translating from language produced in movement, to language frozen on the page. Some of the power of what our storyteller is seeking to convey has become lost in this translation between the media, not just between the words. But, understanding someone else's experience and its importance is, in another way, always an act of translation. We are not there, we are not that person, we are not making those decisions. Yet we want to share others' stories in order to try to understand. It is through the trying that we learn, as much as through the knowledge that we gain. In approaching this story, however, there is some additional scaffolding that the hearing reader might need if they have never had contact with Deaf people before. Therefore, this foreword will discuss in advance some of the subtleties of issues that might otherwise be lost in translation – in both of the senses we have mentioned.

Like any language, there is a culture associated with that language use. In the case of Deaf people all over the world, strong cultural norms of manners, behaviours, histories, perspectives, socialization and family life are inexorably interwoven with being Sign Language users (Sacks, 1989). In this sense, being Deaf is not about hearing loss; it is a culturo-linguistic identity like being Polish or French (Ladd, 2003). This is important to keep in mind when reading this story. If you are not Deaf you are reading this story as a cultural outsider and there will be things you will miss that are important in understanding the complexity of what was happening for mother and daughter. At one point, for example, the author describes how she took her mother off in the car and pulled over on the side of the road to have a private conversation with her about whether everything was really all right. A hearing person might relate to the sense of privacy needed for a sensitive conversation. But the author is saying more. If one's language is entirely visual, someone not in the conversation can nonetheless 'oversee' its content with full clarity of meaning. Physically being somewhere where nobody can see makes the privacy watertight. In describing the location of the conversation the author is indicating to us the extreme seriousness with which she took this talk with her mother and how much she wanted to afford her mother a respectful space in which she had the best chance of talking honestly.

In the UK at the moment there is no clinical service for Deaf people with dementia that is culturally appropriate or available in British Sign Language. No assessment tests have been both translated and standardized for Deaf people in BSL. No memory clinics are run in BSL. Nonetheless, in the story, the author's mother went through the usual kind of assessments with a specialist and everything was translated through an interpreter. So maybe it is not a problem that no specialist services or assessment tools exist? But we know people with dementia can struggle to understand what they are being told, or what they are being asked to do. Imagine how confusing therefore it might be, if questions and information come through a third party (the interpreter). You may not be sure who exactly is doing the asking. Then imagine you are the clinician. You hear the patient's answers through the interpreter's voice a few seconds after the patient has signed them. You cannot synchronize their answer with the extra clues their face and body might betray whilst they were replying. It is like a time delay on a transatlantic phone call – it is hard to tune in to the nuances of the conversation if the timing between the partners in the conversation is not right. Assessment through an interpreter, rather than directly in a shared language, is not the same thing for either patient or clinician.

Other translation effects in tests are more subtle. In the story, the author's mother is asked to remember a sequence of items and repeat them back. In spoken language care is taken to make sure the sequence of items do not sound the same (e.g. 'cat' followed by 'bat') because this might help the person to remember them and so it would not be a good test of recall. In Sign Languages the parallel issue is whether the signs for items might be a similar shape (rather than a similar sound). 'Cat' and 'bat' look nothing like each other in BSL, but 'banana' and 'Japan' do, as do 'England' and 'potato'. The translation into BSL of a test standardized for administration in English thus may create unrecognized advantages of recall that might distort the assessment of a patient's abilities. It might be easy to remember what looks similar, but because the words in English do not sound the same the administrator may not know this effect is occurring. Also, not all signs are iconic (i.e. look like the thing they represent) but some signs are. Perhaps in a translated list of items many of them will be iconic (e.g. apple, cup, window, elephant) and therefore maybe easier to recall, than those that are not (e.g. bed, pink, biscuit, New York). But spoken English has no such distinction of iconicity so the lack of equivalence in the translated test will be missed. There has been no systematic study of the validity and reliability of the MMSE when used with the Deaf population. However, studies of its use amongst culturally and linguistically diverse hearing populations (Basic et al., 2009) have suggested that it may be less effective

at detecting the early stages of dementia because it has not been standardized on those populations.

There is no network of support groups for Deaf people with dementia in the UK. As the author comments, the only available support would have been groups for hearing people with dementia, but her mother would have had to participate through a third party, an interpreter, telling her what everyone else was saying and being her 'voice' to them. The benefits would be lost of sharing direct and personal contact with others facing a similar experience. She would be an outsider in a group who did not understand her – a situation that would hardly qualify as support. Yet, as the author discusses, the need to keep mentally active through interaction with others in a shared language is vital for someone with dementia. However, for someone Deaf with dementia who uses BSL, there was nowhere to go.

General knowledge in the older Deaf community about dementia is poor. Providing information in English is not necessary helpful. A great many Deaf people have very low levels of English reading and writing regardless of their fluency in BSL. The author tells us about her search on the internet for information, but goes on to remark that although there was a lot of information available, there seemed to be little (information or support) 'for us'. That 'us' is culturally a powerful statement. It is not an 'us' that refers to the particular family in question, but an 'us' that refers to the whole community of those sharing the language and ethnicity of being Deaf. There is little out there 'for us'.

Conrad (2004) makes a similar point in an account by a hearing daughter of her Deaf father's experience of support when his Deaf wife developed dementia. With an interpreter, he attended a carers' support meeting:

The meeting was a disappointment, through no fault of the participants. I should have known how Dad would react to a group of hearing people. As he'd always done with strangers, my father smiled politely, nodded, answered questions briefly and volunteered nothing. What he really needed was a group of deaf folk – people he would trust – going through the same experience. The Alzheimer's connection was not nearly enough to break down the walls between hearing and deaf cultures . . . We never went back. (Conrad, 2004: 234)

We do not know how many Deaf people experience dementia. We cannot trust that Deaf people with dementia actually come to the attention of services or that their needs are appropriately recognized. In the story below, see how the author took her mother to a GP who could not see there was anything wrong. But then how could he? He literally did not see her mother's language, or her mother's thoughts through that language. He heard an interpreter. He spoke to an interpreter. And for whatever reason,

he did not believe her daughter. Was that because she was Deaf too? From the author's perspective her mother was 'becoming quieter' and this was an obvious cause for concern. But how would hearing people generally be able to spot such changes, if to them the patient was always 'quiet' because they did not speak? Within hearing environments an older Deaf person's lack of interaction can too easily be attributed to communication barriers rather than being seen as a sign of possible cognitive decline. In the author's case, she was left to interpret culturally her mother's behaviour to the clinician attempting to make a judgement about her mother's well-being at the same time as being distressed herself about her mother's health.

Because of the lack of research relating to dementia and Sign Language, we are unclear how, as dementia progresses, BSL users' language might change. We have no idea what might be typical or indicative. In the story, the author, for example, noted many changes in how her mother was communicating – sometimes seeming to sign when nobody was there or pointing and moving her lips without speaking. She was not communicating in a way that made sense to those around her. However, if someone did not understand Sign Language how would they necessarily be able to see that such communication was nonsensical? They might have thought it typical of a Deaf person.

We have no research on the experience of dementia from the perspective of Deaf people themselves. What it is they value and would wish to preserve in their journeys through dementia, might be so totally different (or not) from the experience of hearing people, or the experience of those in other cultural communities. Nobody has ever really asked. We have no research on the experience of Deaf carers like the author in the story below. We believe this is the first narrative from a Deaf carer ever to be in 'print'. The author of this story is well educated, has good English, is embedded in the Deaf community and works in the mainstream world. She has many advantages to steer through the unfamiliar territory of dementia services and for her it was still a struggle to understand and be understood. What of many older Deaf people, who are now carers, from generations who had little access to good education, who have fewer personal and social resources to gain knowledge, battle systems and overcome barriers? Their narratives are unseen and in being literally unseen, they are unknown.

At the end of the story the author reflects on what might have been different. The overwhelming message is the damaging effects of communication isolation. Whatever the merits of the residential care the author's mother received, she was still living her final years in an environment where nobody signed so nobody understood her communication. She saw no conversations happening around her that might have kept her in touch.

She had no social stimulation through shared interests and activities with others she could communicate with. There was nothing culturally familiar to echo her Deaf history and values (the pictures on the walls of the home might have been of film stars in the 1940s and 1950s, but where were the familiar images from Deaf culture in the past?).

Nobody has yet proven through research whether communication isolation is more common for Deaf people with dementia and if so whether it makes worse the decline associated with the illness. However this daughter in this story is quite clear that it did. From a Deaf perspective her mother died in a care environment that was an uncommunicating world, but it was the best available at the time. She and her sister had an unenviable decision to make – to choose between a care home with other Deaf people but where the care was of poor quality and did not fit her mother's needs; or a home offering a high quality of dementia care but where she would be the only Deaf person. In some countries this kind of judgement of Solomon does not have to be made. In the Netherlands, for example, there is a purpose-built Deaf residential care facility where all residents and staff sign and graduated care is provided for older people as needs and degrees of independence change (<http://www.gelderhorst.nl>). In the UK, services for Deaf older people in general are few and far between and specialist services for Deaf people with dementia virtually non-existent.

Finally, in her moving account, the author describes her last conversation with her mother; fluent and unimpeded through their shared language. Whether her mother at that stage 'understood' her and could communicate back was of less concern than the fact that she knew her daughter was communicating with her and could literally see that communication and through it her daughter's love for her. Yet, how was it that the author found out her mother had died? The primacy of the spoken word once again intervened and the care home telephoned the hearing member of the family, but did not contact her directly. Email, text and telephone relay services are now all available to make direct contact between hearing and Deaf people an everyday reality. However, many Deaf people still regularly experience the most personal and serious information sharing through a third party, oftentimes because from hearing perspectives, it is perceived to be an easier option.

We sincerely thank the author for her story below and for allowing us to use it to raise these complex issues. We invite you to share her translated experience.

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Alys Young
Katherine Rogers

My Mum's Story

My mother truly was an amazing, loyal and respectful woman. She was kind and generous and always ready to help others. She loved children and was always very encouraging to them; she got on so well with kids. My mum was Deaf, as is my dad and they had two daughters – myself, also Deaf, and my older sister, who is the only hearing one in our family. My mother always kept herself very busy looking after my sister and me, making sure we were well dressed and fed and clean and happy. She was committed to bringing us up well. She was a very influential person in my life. She worked hard and was always active – she worked part time as well as caring for us and every day she would walk the two miles to her job as a machinist after getting up early to help get us ready for school. Once she'd finished work for the day she'd head home and made tea for us all before doing the housework or sewing – she used to make clothes for us and would sometimes take on sewing or knitting jobs for other people too, making clothes or curtains or whatever. Honestly, she was always on the go and had a very full life. I can't remember ever seeing her just sitting down relaxing, or asking any of us to do things for her, it just wasn't her way. Even when my dad did any decorating or anything, she'd be rushing round after him, cleaning up! It was just her way.

I remember her telling me that, as a child, she'd attended a School for the Deaf as a boarder. She'd only return home to see her family at Christmas or Easter or through the summer break. She was happy there though and had a lot of friends but missed her home and family. She was very keen on sports as a child, particularly hockey and I was surprised to learn that she was even good enough to play for England in her youth! But then she

married and had children, so she gradually drifted away from hockey. She told me it was because she was determined to make her family her number one priority. Her role as a mother was the most important thing to her. I said she should have carried on her hockey; that she could have managed both, but she was adamant that we had to come first and that was that – as long as we were happy, she was happy.

She worked in the same job right up until she was 65, when she retired. She could have retired at 60, but she would have been bored, so she stayed. She worked for 40 years there as a machinist, combining that for a lot of the time with looking after my sister and me and the stream of friends we used to have round visiting. I thought maybe she'd give it up at 60 and try something different, maybe do something more interesting, but she didn't. When she finally did retire, at 65, I told her it was her opportunity finally to relax, enjoy herself, pursue her own interests and get out and see places, and, to her credit, she did. She used to go out for lunch with her friends, go to bingo regularly at her local Deaf Club and on the Deaf Ladies trips every year.

My prevailing memory of my mother in those days is of her smiling. She was the kind of person though that would always keep any problems she may have had to herself; she was never one for sharing things like that. She was too proud I think and she felt she had to put a brave face on things. She was an attractive woman and always well turned out. She was sweet and generous and she was also proud of her ability to soldier on and she always swept problems to one side. She didn't see them as important in the greater scheme of things, and she felt it was important to project a happy persona to the world.

After she retired though, I did start to notice a change in her. She seemed quieter somehow. She'd always been a chatty person, talking ten to the dozen the whole time, but to me she seemed to talk less and she didn't seem as happy as she always had. It was significant enough for me to bring it up with her and ask if she was alright on a number of occasions, but she always brushed it off and said she was fine. I was worried that she might have something on her mind, but she insisted nothing was wrong. On one occasion, we went out together in the car, just my mother and me, and I pulled over and asked her again. I thought maybe the fact that we were in a quiet place where there was no chance someone would oversee us talking would convince her to open up. I told her she could confide in me, that she could tell me anything and I would keep it secret, if that's what she wanted, but she just laughed and said I was being silly, that there was nothing wrong at all, that she was fine.

I stopped asking after a while, but that feeling at the back of my mind that something wasn't right never left me. It nagged at the back of my

mind and eventually I brought it up with my sister and asked what she thought. She hadn't noticed anything out of the ordinary though and thought mum seemed fine. When I told her what had started me worrying she just put it down to mum being like that sometimes, but I still felt certain that something about her was different somehow. I asked my father too, but got the same response from him, so I tried to leave it. I just put it down to me, but after a while, it seemed that my mother was getting worse. This all took place over a period of about two years. The change was gradual, but my mother seemed to have gone from a cheerful, smiling, happy, patient person to someone who was moody and often sad and irritable. I noticed changes in her personal appearance too. She'd always dressed very smartly, but now she was taking less care with her appearance. I was sure something was wrong.

I finally brought the matter up again with my father and he agreed. Both my father and sister realized that something was wrong in the end too. I had even asked one of the members of her local Deaf club and she said she and others had noticed some changes too. It was such a relief to me that finally someone else could see what I was talking about. We talked about what we'd both noticed and dad said that mum had been forgetting things lately. I decided it was high time she was seen by a doctor, but it wasn't easy to persuade her to go! When I first suggested it, she wasn't having it at all and refused point blank, saying there was no reason for her to go, that she was fine. I had to drop the subject because she wasn't going to budge, so I had to think of a way round her refusal. When I asked again, a bit later, I cooked up a story about something I'd seen on the internet which said all people over 65 must go to the doctor for a health check, due to the changes people go through as they get to that age.

She finally agreed to go, on the back of what I said, and I went along with her, as well as taking an interpreter, to make sure that we could understand the doctor and vice versa. At that time my sister was away. The GP was a bit confused at first to be confronted by the three of us. He did not see the point of all three of us being there, so I had to explain why we were all there together. I went through a list of all the changes I had noticed in my mother's behaviour and appearance, but after taking a quick look at her, the doctor was laughing and dismissed my concerns, telling me I was just being silly and that it was all perfectly normal for her age. I insisted that it was not simply a question of her age, but that something was not right with her. It certainly wasn't normal for her to be forgetting things all the time. I firmly asked that he refer my mother to a specialist but he was reluctant to do so, saying that it wasn't necessary. I was infuriated that he wasn't taking us seriously and insisted that he give us a referral, refusing to leave his office until he had done so. He agreed to do so in the end, but

only to humour me, I'm sure, as I could see on his face that he thought it was just a waste of time.

Quite quickly, a referral came through to the Memory Clinic at the local hospital, where they deal with dementia, Alzheimer's and so on. Again, I went along with my mother for the appointment with an interpreter and this time she was given lots of specialist tests, mostly consisting of questions she had to try and answer, such as where the queen lives or what year we were in. She was also given tasks where she had to remember particular items and repeat them back in the same order. All of this was done in translation, through an interpreter. As she went through these tests I could see she was getting many of the answers wrong, the majority of them, in fact. Actually seeing that happen made me realize that things really had become bad. After the testing, the specialist came through to talk to my mother, again I think as a way of testing her memory and her responses. I was really shocked to see that she didn't seem to be following the conversation at all and that her responses to the specialist's questions were just way off base, not related at all to what was being talked about. Throughout all of this, I'd sat in the background and just watched. Once the doctor had finished all the tests and had looked at the findings, he addressed my mother (through the interpreter) and told her that he'd completed the tests on her, and they showed that she had Alzheimer's disease, which was affecting her memory. My mother just looked at him blankly, but I burst into tears and was comforted by the nurse. My mother looked round at us and just asked why I was crying. I asked the specialist a couple of questions that I wanted honest answers to. How long did she have to live and was there anything that could make her better? He told me that some people live with it for many years and with medication the deterioration can be slower but without treatment the deterioration could be quick. He told me it was incurable. When we left and got outside, I was still very upset and crying hard. The interpreter was trying to console me and my mother joined her, telling me not to cry and asking what was the matter. I couldn't believe she hadn't seen what the doctor had said, but she didn't seem to recall it and I realized she'd not understood, not taken in what he'd said to her. I had to wipe my eyes, pull myself together, calm down and just get both of us home.

When we did get back, mum went off to do her own thing in another room as if nothing was up. I took my father to one side and told him what the specialist had said. He cried too. When my sister got back from her holiday, I had to break the news to her too. She was devastated. We all were. We were all over the place at first, then we got Social Services involved, as we thought they could help us by telling us what kind of support there was out there for people with Alzheimer's. We didn't know where to turn

to for help or for information. Obviously, my mum was our priority and we did what we could to support her, but it was a difficult time. We found that while there was a lot of information available about the disease itself, on the internet in particular, there seemed to be very little actual, practical support out there for us. There was nothing in BSL. Even Social Services didn't seem to know what to suggest or do and we expected them to be the experts in knowing what kind of help was available for someone who was Deaf and had Alzheimer's.

I felt that my mother would benefit from keeping active, attending groups where she could maybe get involved in crafting things, keeping her brain on the go and stimulating her memory. But there was just nothing for her. Everything we did find out about like that was for hearing people and while I suppose mum could have gone along with an interpreter, the level of interaction would just not have been the same at all. Ideally, she would have been able to do something like that with other Deaf people with Alzheimer's, but there simply wasn't anything set up.

My mum's Alzheimer's was beginning to take its toll. She collapsed and was taken into hospital. When my sister and I visited, we took an interpreter with us so we could all have full access to any information from the staff. To our frustration we were told off by the nurses because only two visitors were allowed! They just did not understand the interpreter had a professional role. She was not just another visitor. In the end we were allowed to stay but I was so very upset. A very difficult situation was made worse by their lack of Deaf awareness.

We struggled on, just doing the best we could, until my father developed a problem with his hip and needed to go into hospital for an operation to put it right. My father was the main caregiver for my mother at that stage and was with her 24 hours a day. Who was going to take over if he went into hospital? I was willing to give up my course and my job to look after my mum, and told this to someone from Social Services who commented that I was wonderful to do this. I then told this to my family and friends, but they were concerned and thought that I should think about it carefully. I had my own life and mum would have wanted to see me happy. It was really a hard decision. We felt the best thing would be for mum to go into respite care for a while, so we started looking at homes in the area that might take her. A number of friends informed me that there was a care home somewhere where there were other Deaf people residing. They thought it would be good company for my mother. We went for a look round and it seemed ok and it was near enough to be practical for us all, so we decided to go ahead with that. This was a really hard decision. I remember a conversation I had with my sister before my mum got ill, when we said that we would never put my mum in a home, but it did happen.

Some people thought this was a wrong thing to do and that we should look after her but we are not a big family who could have taken it in turns to look after her. I have to say I hope they would have more understanding if they were in my shoes.

Unfortunately though, it quickly became evident that things at the care home were not what we had hoped. The atmosphere there left us feeling very uncomfortable and the attitude of some of the staff towards the residents was very poor, particularly the Deaf residents. They often shouted and harangued them and handled them roughly when there was really no need for it. We took the decision to get my mother out of there as quickly as possible. I felt sorry for the other residents too, I thought things needed improving there but I had to focus on my mum.

Then we had the problem of finding somewhere else. The other places we considered were either not suitable or were just too far away from us to be practical. We wanted mum nearby so that we could all visit regularly. We couldn't find anywhere else that had other Deaf people staying, so we resigned ourselves to having to put her somewhere where she was likely to be the only Deaf person – we didn't have any choice. My sister and I searched all over for somewhere we were happy with and eventually someone told my sister about one place where she thought my mum would be happy. Although it was situated in a really rough area, it was lovely, really nice, newly built and just right. As you walked into the main hall, each resident had their own room, with a proper front door type door, just like a door into someone's home. Each door had a doorbell and a number and a little spy hole so the person inside could see who was knocking. There was a name and a picture outside every door too, to help the residents remember who was who and where their rooms were. It felt more like an apartment building than an old people's home. The walls between the doors were decorated with photo prints of old film stars like Marilyn Monroe and Clint Eastwood, and Mohammed Ali. The place had a lovely, old-fashioned atmosphere and I'm sure the décor helped residents think of fond memories past. The complex was divided into three sections, depending on the severity of residents' condition. My mother was placed in the moderate wing. On the whole it seemed like the best solution, but I was still concerned about how my mum and the staff and other residents would communicate. This situation was made worse because a few of the staff on nightshift were from overseas and English was not their first language.

But, moving in to that place was great for my mother. She started smiling again and seemed genuinely happy there. Eventually, the family decided it would be best if she stayed on there, so we approached Social Services to arrange for ongoing funding to pay for her care. We ran into problems then, because Social Services were very reluctant to do so and

told us she would have to move to a different home. We refused, saying we had looked at the other homes in the area and were confident that this was the best place for her. Much arguing followed.

My mother turned 70 at this time and had been living with Alzheimer's for three years. We decided to arrange a special party for her at the old people's home she was in, so we invited about 20 of her old friends to come along and celebrate. We laid on a big spread of food and brought in a birthday cake and everyone really enjoyed themselves and we took a lot of photos. My mother looked so happy that day, almost like she was back to her old self, chatting away with friends in Sign Language, smiling and having fun. Everyone commented on how well she seemed and how lovely it was to see her looking so happy. She really had a wonderful day. I persuaded someone to put together a kind of photo-book for mum, full of pictures of her when she was little, of her family and friends as she grew up, of us kids and so on for her 70th birthday present. I thought the pictures in the book would act as a stimulus to help her to remember things from her own past. I showed her the draft copy of the album, and she was smiling when she looked at the photos of her past.

The arguments with Social Services about my mother's care dragged on and on. Our allocated social worker was quite supportive in principle, but said they simply had no resources or funding to pay for it, making it difficult for them to do anything to help. My sister and I held our ground though and kept fighting for what we felt was best for mum.

Two weeks after the party, I was at work and I had this nagging feeling that something was wrong. At about 2 pm I couldn't stand it any more and I got up, put my coat on and told my colleagues I was leaving to go and see my mother. They all looked a bit surprised because normally I would have let them know I was leaving early, but I just said I was going and that was that. They were left wondering what the hell was wrong with me. Anyway, I headed straight round to the residential home to see mum. She looked a little different, but I couldn't say why. It was a beautiful sunny day outside so I suggested we go out to see the birds and maybe feed the ducks, get some fresh air and have a bit of a walk. I could tell my mother did not really want to go out (although she couldn't say so) which surprised me because she never turned down the chance to go out; she loved the outdoors. I tried to persuade her, as I thought it would do her good and she eventually agreed, so we headed off to her room to get her ready. When we set off along the corridor to the main door though, I noticed that she was walking funny. Her balance seemed off and I really had to work hard to steady her. When we approached the door, mum became quite agitated and panicky, suddenly she'd changed her mind and she didn't want to go outside. I tried to calm her down, but she had scared me; I didn't know

what the matter was or why she was so upset. I started to cry because I'd never see my mother all panicked like that.

The staff came to help and we got her sitting down, though she was still shaking and repeating that she didn't want to go out, despite us all telling her it was OK and she didn't have to go out if she didn't want to. Someone brought her a cup of tea and eventually the shaking subsided and she calmed down, but the whole episode really left me shaken. I suggested that she might like to go to bed for a rest and she agreed that she did so I took her back to her room and got her laid down quietly.

By now it was 3 o'clock and I was late for the big meeting with Social Services where they were going to make a final decision about my mother's care. I knew my sister would be there, so I wasn't too worried, but I texted her anyway to say I would be on my way as soon as I could but that I was running late. I stayed with mum just stroking her beautiful shiny hair just like she always did with me when I was little and keeping her calm as she dozed off. Her eyes were kind of glowing and glazed over, they looked really beautiful, shining, and she was smiling at me. I told her to go to sleep, to have a rest and I told her how much I loved her, which made her smile even wider. I talked to her, saying soothing things and she was smiling and nodding but she didn't really seem connected, it was like she was looking at me but not really seeing and she was somewhere else. She told me she wanted to 'go home' but I knew she didn't mean her house but somewhere safe to be with her family. Her eyes drew me into her world, the world she was seeing now but I couldn't see. I felt so much love for my mum at that moment. I waved her goodbye and told her I would see her later.

Eventually I left to head off for this meeting and after some discussion it was finally agreed that the funding would support the care for my mother to stay in the home she was settled in and that we were happy with. It was such a relief after the difficulties we'd had with them. But after the meeting I could not shake off the feeling that there was something wrong and I told them that my mother wanted to go home. Their faces looked really puzzled – what I was talking about? My sister asked me when we left the building if I was OK so I told her and she rang the home asking if my mum was OK. They said she had just woken up and was sitting in the lounge, having tea and smiling.

The next day, early in the morning, the home called my sister and told me that my mother had passed away. I was heartbroken. My mother only lived for three years after being diagnosed with Alzheimer's. Looking back now, I can see how the disease really affected her vocabulary, which became severely limited very quickly. The progression of her illness and her decline was very fast indeed and the treatments that were available didn't work for her. She tried three different medications over that period but none of them

worked and she also suffered bad side-effects from them – they caused her to vomit and feel ill. In the end, she stopped taking any medication, which is partly why she went downhill so quickly, I'm sure. I also feel that her decline was hastened by the lack of resources available to her. There was nothing offered to help stimulate her mind, meaning her faculties faded quickly, along with her vocabulary. Her oldest and closest friend also stopped visiting and trying to communicate with her. I'm not sure why, maybe she was afraid but she never asked me about my mum's illness and she stopped making an effort. Sometimes my mum seemed to be in a world of her own, signing to someone but nobody was there; reaching out for something but nothing was there, pointing and moving her lips but she wasn't talking. None of us could understand what was saying. By the end she could barely speak or sign at all. She even stopped saying thank you or hello and was reduced to just smiling a lot of the time.

Looking back, I can think of many things that could have been done better for her – better service provision, better available resources, more stimulation and so on. The Social Services tried their best, but from my perspective it was not enough. Some mental health specialists used to working with Deaf people also tried to help and did some assessments. But they were used to treating mentally ill Deaf people, they were not trained in treating Deaf people over 60 with dementia. At the time it was better than nothing, but looking back we should not have had to make do. I really believe that her decline could have been slowed considerably and she would not have gone downhill so quickly if her dementia had been spotted earlier and proper specialists who were trained in dementia and used to Deaf people had treated her. The lack of structured activity in her life, and the lack of company and conversational stimulation, led to a shrinking of her ability to communicate and interact with people and with life in general. Things should have been better, really, but it's too late now, my mother has passed away and may she rest in peace now.

Notes

1. A note on the production of the text: The story above was originally produced in BSL in conversation with a Deaf researcher [a shared linguistic and cultural experience]. It was translated into English by a Deaf and hearing professional translation service [a bilingual approach]. This introduction was written by a hearing researcher in collaboration with a Deaf researcher [a cross cultural text]. Any edits of the story and this foreword were checked by the story's author who read them in English with clarification provided in BSL [a bilingual and bicultural validity check].

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