The Cancer Professionals Podcast

Creating accessible cancer care for Deaf people

Episode transcript

Note: The guests in this episode (Claire and Gillian) communicate in British Sign Language (BSL). Their responses are voiced by a professional BSL interpreter. All dialogue attributed to the guests represents the interpreter's spoken interpretation of their signed responses.

(Intro music)

Carly (00:10)

How can we expect a person to make informed decisions if the very information they need is out of reach?

Claire (through interpreter) (00:16) – Clip from episode

A lot of Deaf people who get in touch with us are often saying, what does this word and that word mean? There's a lot of that kind of terminology in these letters. And so we, yes, we break it down and we explain what it means. There was a case of somebody who was diagnosed with a blood cancer. They went to hospital for a treatment. They assumed it was for a kidney infection. They didn't even know it was chemotherapy.

Carly (00:39)

Hello, I'm Carly and my pronouns are she, her.

Paul (00:42)

And I'm Paul and I go by he, him. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, including health and social care professionals to lift the lid on current issues faced by cancer workforce.

Carly (00:58)

If you enjoy this episode, please subscribe, rate, and share with your colleagues and friends. We'd also love to hear from you. Please get in touch, ask questions, give feedback, or even suggest topics you'd like us to cover by emailing professionalspodcasts@macmillan.org.uk or by filling in our short survey linked in the episode description.

We are thrilled to announce that we're moving from monthly episodes to a new bi-weekly schedule, bringing you even more insights, stories, and expert conversations every two weeks.

Paul (01:28)

Today we're joined by Claire Adshead, Macmillan Deaf Cancer Support Project Manager and Gillian Briden, who shares her personal and at times very challenging experience of cancer as a Deaf person. It's an important conversation about improving access, communication and equity in cancer care.

Carly (01:49)

This episode contains conversations about lived experience of cancer, which you may find upsetting or triggering. Listener discretion is advised.

Carly (01:58)

Welcome to The Cancer Professionals podcast. Shall we start with some introductions to tell us about you? Gillian, shall we start with?

Gillian (through interpreter) (02:09)

My name is Gillian Briden.

Claire (through interpreter) (02:17)

Hi, my name is Claire. Claire Adshead. I am the project manager for the Deaf Cancer Support Project.

Gillian (through interpreter) (02:25)

I forgot to say who I was. Should I say something afterwards?

Carly (02:29)

Yeah, so can you tell us a bit about why you're here today?

Gillian (through interpreter) 1 (02:36)

Oh, from the start? Yes. Tell my story. I was diagnosed with bowel cancer in 2010 and I was very, very ill. I went to the hospital however there were no interpreters. For 15 years, well, I'd say for the first three years there was no interpreter.

Claire (through interpreter) (03:08)

We support Deaf patients through their cancer journey and we try and help them with breakdown communication barriers, for example, making sure interpreters are provided, trying to translate jargon terms, giving them emotional support and helping them along their journey so that they're not anxious all the time and stressed. We try and reduce that level of stress and at the same time, try and educate the hearing professionals how to make reasonable adjustments that help the Deaf patient along on their journey ~ to make sure that the information they're given is accessible, provided in BSL or even if it's a leaflet in a more visual format.

I know that Gillian's story is one of the examples that we've seen, one of many over the country, where we've seen that the adjustments really should have been made. And I know that she wants to tell her story today.

Carly (04:06)

Yeah, absolutely. And that's such a long time, as you shared, to not have an interpreter. Gillian, would you be happy to talk a bit more, as Claire said, to share your story and some of the things that happened along that journey? Would you be okay with that?

Gillian (through interpreter) (04:23)

Yeah, that's fine. Well if I go from the start, that's July 2010. I was having problems, I was losing weight and I didn't know why. I was struggling to walk, I had breathing issues, indigestion, it was affecting me a lot and I went to the doctor. I explained all this problem and the doctor just said, it sounds like indigestion. I was like, okay.

So I was given tablets, but it just kept on getting worse and worse. So went back to the doctor again and said, this indigestion, it can't be that, there's something else going on. So I went for a blood test and I realised that my blood count was very low and I needed iron tablets. So I was on iron tablets every day. I said, was okay, I'll take these tablets. But I really was getting thinner and thinner and I went to the doctor and said look I've lost so much weight before I was 12 stone something and now I was eight stone so you know something wasn't right and I received a letter from the doctor saying I had to go to the hospital so I went and they were doing all sorts of they a gown and all this and they were showing me stuff I had to do but there was no interpreter there at all.

So I had this gown on and then they gave me something to make me sleep and told me to lie down and went in this machine and I had a tube down my throat and I wanted it to come out because it felt horrible and I was like, please take it out and they were like, no, you have to have this tube, just one more, one more, they kept saying. And then I had one up my bum and that really hurt. And then there was a picture and I could see like a ~ some kind of something on the screen but I just wanted everything out but the doctor was ~ shocked that I was sort of still awake through all of this and then I had to go into a waiting room and there were these other beds there and my daughter came was there as well and I was just saying I don't know what's wrong and then the nurse came and I said look what are we waiting for why are we here and the nurse wrote down

You have got bowel cancer. And I just, my mind went blank. My daughter was there as well and I could see she was upset but didn't say a word. And the nurse just said, oh, go and get changed. And I did. And I went home, told my family who were all really upset. But I really went downhill after that. I was so thin, so pale.

I saw the doctor on December the 20th. This was at the hospital. And again, there's no interpreter there at this appointment and they were writing things down and trying to draw things and trying to explain to me where my cancer was. So they sort of drew my bowel and said, you're going to have to have this bit and this bit cut out and then sewn together. And they said, oh, you'll be fine. And you'll be able to drink red wine. I was like, okay.

I didn't really understand quite what they were saying because no interpreter was there for that appointment. And then January the 20th, back at hospital and had the operation on the 21st, which was a Tuesday. There was no interpreter present through any of this operation. I was sobbing, I was upset. I was just in this bed on my own. I had to drink some stuff that I didn't really understand why I had to drink it.

Tuesday morning, I went down for the operation at nine o'clock. My husband and my daughter were there trying to help interpret as best they could because I didn't have an interpreter. It was awful. Went in for the operation and then I was in, what do you call it Claire? Yes, the recovery room. I remember coming around in the recovery room and my husband had been waiting for me there and you know.

He wanted to come in but the nurse said, you're not allowed because my husband just wanted to reassure me. Then, oh no this is terrible, on the Wednesday morning I was getting quite angry because I had these socks on my legs and I think it's to stop blood clots. But I wanted to take them off. I was trying to get them off myself because they weren't comfortable and you know I was just trying to get them off. And the doctor came along and I was like, yeah.

I've done this and they were like, you're doing well, you can go home on Friday. And I was quite surprised. But I could feel my face coming back, there was colour in my cheeks again. And you know, my friends were happy and they could see that I had some colour in my cheeks. So I went home on that Friday, but I had had an interpreter through none of that experience whatsoever.

Got home, then six weeks later, I went to hospital to start to talk about chemotherapy and there was an interpreter there but it was just talking. So they were discussing about I'd have to have chemotherapy now for 12 weeks. So I was like, okay. And they said, there's, you're not going to be able to, your feet might feel funny, you're not going able to drink ice cream or cold drinks, you know, you might experience problems like that. So that was good, so said okay, thank you. However, for the entire course of chemotherapy, I then had no interpreter.

Now what they did on the day was they'd give me a bag of tablets every two weeks, I'd take them home, put them away. I had no idea what these tablets were supposed to be for, nobody had explained to me what they were for. All I was taking myself was paracetamol for that 12 week period. And the 12 week period was finished. I've got all these tablets in my bag. Went back to the hospital to return them. The nurse opened up the bag. I could see from her face, she's like, why aren’t you taking these tablets? I said, I don't even know what they are. And then just sent me, they had sent me home with them and said goodbye each time and never explained at any of the sessions what they were for. And I hadn't had an interpreter. So yeah.

They never explained why I should have been taking the tablets. So that's why in my opinion, I needed an interpreter there because I hadn't had anything explained to me. So that was that session.

Then in 2013, I remember my daughter had to have a smear test and she said I should have one too. And I was like, really? She said, no, you really ought to have one. So I did go for a smear test and I was waiting for... two or three weeks and hadn't heard anything and I got a letter back saying I needed to go to the hospital. So went up to the hospital and then obviously you know you had to have your legs apart and there was no interpreter and a man came around I said I don't want a man doing this investigation I want a woman please and the man said okay so a woman came to do the test and then I went home I received another letter to say I had to go to the hospital. So off I went.

I arrived and then they were suddenly saying about, you know, needing an operation and I was like, what are you talking about? I didn't know what they might be talking about and they hadn't been in touch and said anything so I did need to this operation. About six o'clock I was in a real pain and I woke up to find there was a tube and a bag, like a catheter which I didn't, and I was like, can you take this out? And they were like, no, you can't take that out, that has to stay in, and I didn't understand why it was there, I was in pain, uncomfortable, till 12 o'clock, and I said, what's this for, it's painful, I want it out. And they told me there, you've got a bladder tumour, and you need this to put an injection in it. And this was, again, the first I'd heard of this, and there was no interpreter at all. So I still said, this is really uncomfortable, and they did allow me eventually to have it taken out about 12 o'clock in the evening and then I went home but again during that discovery of bladder tumour I had had no interpreter.

Two weeks after that I'm returning back to hospital for a hysterectomy and there was no interpreter for my hysterectomy so I had to have my womb removed because there was a risk of cancer, but there was no interpreter. That made me feel really low and I started to think, why me? And also I hadn't had an interpreter. I feel like if I'd had an interpreter, I would have understood what was happening to me. No one told me what I've later discovered. I had Lynch syndrome, but I wasn't told anything about that at all. ~

So then I went back, maybe it was nothing for two years and then ~ a doctor said at one point, wow, you're okay, but you know, you're doing well. You've had three cancers. And the doctor was saying, you're amazing. A lot of people would have given up, but you've kept on fighting. And I said, well, I think of my three daughters. I want to be positive for them. And he was like, ~ but I was like, surely, you know, that would be the case for most people. But this doctor said, buh-bye, don't come back, you're all finished. So I thought I was finished with everything. And I was obviously really happy that I'd survived three cancers. And then many years passed. And then unfortunately, let me get this right, three years ago now, I went to a wedding and I, I'm not sure how to spell this. I had what? risotto which I really enjoyed and then the point where you have to say cheers and congratulations I felt really sick and so I thought is it indigestion perhaps took some tablets I didn't think anything of it and then November that year my family went out to the pub for something to eat and again I was sick and I thought hmm then Christmas time we got through Christmas but then in January I had swollen glands twice on my face and my teeth weren't great but I was like no it's my toothache because it's swollen glands somewhere but I felt very weak and my daughter Mandy ~ was quite angry and said, look, I think you need to go to the doctor and get some blood tests and get this, you know, you've obviously got an infection of some sort. Anyway, I had a blood test and I was sent off straight away and they said, that I didn't have bowel cancer at that time, but they did a scan, they did a CT and it felt like there must be something there.

So in the end I did a PET scan and that was fantastic where you could see everything and that's the point when they did find that once again I had bowel cancer. So there was a doctor sitting on the bed, there was myself, my daughter was there and the doctor said, did you know that your previous hospital had said to you that you had Lynch syndrome and I said no I didn't know anything about this what do you mean and apparently this Lynch syndrome is why I'd had all these cancers coming back you know over 15 year period and I should have been rechecked every two years and that hadn't happened and I will have to be checked every two years for life but they said you know you've now got this other tumour and you know you have got Lynch syndrome and you're going to have that for life and I was very upset, burst into tears and I just think, you know, why me? It's so unfair. But like I say, at that appointment I did have an interpreter so at least I could understand. But yeah, I've got this Lynch syndrome and I've got it for life.

I thought I was better, but I'm never going to be better. I'm going to have to the checks every three months. At the moment, I'm having chemo at the moment, currently. On November the 24th, I've got a scan to see if that tumour has reduced. I don't know whether I might need a different injection or anything, but yes, I'm going to have to be checked every three months for life and it's really sad and I have to be strong for my family.

Carly (17:28)

Oh gosh, Gillian, I can't even imagine that such a long time, a long journey for you having those cancers. And also it sounds so distressing to have all those things happen, the treatment, the surgery, the tests, and have such a long time where you don't know what's happening. You haven't had that explained to you. I can imagine that must have felt so, so scary.

Gillian (through interpreter) (17:57)

Yeah. But why? The hospital should have provided an interpreter. They just, you know, and also telling me that after my third cancer that I was clear and I could just go home and not think about it again, that's really bad. I feel I wish I knew earlier, then I, you know, I might have been saved a lot of the issues, you know, if I could have been, if this could have been discovered earlier. It's too late now.

Claire (through interpreter) (18:34)

From listening to Gillian's story, I have to say she's not an isolated case. This has happened all over the UK to Deaf people. I'm hearing more and more stories like this and it shouldn't be that way. Everybody should be equal to get accessible access to their care and information about their care in their own language. Deaf people face additional barriers because our language is sign language (BSL). Hearing people who use a different spoken language, I know the hospitals generally use a telephone interpreter, so that's what they're used to doing. However, with BSL, a visual language, really we need a face-to-face interpreter there to get appropriate care and to understand what's happening to us. And it's still happening out there now where Deaf people aren't getting interpreter access.

And we really need to reduce that by educating health professionals, spreading the word, learning what it means, you know, what Deaf awareness means and how to help Deaf patients in the best way so that doctors, nurses, pharmacists, oncologists all know and that patients are then fully informed about what is happening to them. When you know what's happening and you know what to expect, it's much more reassuring as a cancer patient. Gillian's story is completely the opposite. This should never have happened like this. However, as I've said to you, it is still happening.

Paul (20:08)

So Gillian, thank you for sharing your story with us. And Claire, if I could come to you, could you tell us about the Macmillan Deaf Cancer Support Project? How did it start and what does it offer?

Claire (through interpreter) (20:35)

Originally it started in 2016, it was one person, a lady who had breast cancer and had a friend supporting her through that cancer journey. Unfortunately the person with breast cancer passed away but the friend campaigned to Macmillan to get some funding for a project for Deaf people. Two men originally tried to set the project up and they were both hearing and it didn't work.

So what they did was they advertised for a third person to join the team and a Deaf woman joined at that point and the two men were taken off the project basically and then it was in Derby where the project started. So it was a local project initially until 2018 when they got further funding because Matt Macmillan could see there was a demand and that the project could benefit more Deaf people. Deaf people needed support. So the woman who was involved at the time was supporting a lot of people in Derby and Nottingham with their cancer journeys, providing emotional support, translating letters into BSL and general support.

Then in 2022, I joined the project. ~ So I was originally the peer group officer and the project went national with Macmillan's help. So we were able to go further out and about nationally supporting Deaf people with cancer all over the UK, including Northern Ireland. So what we do now is we provide emotional support. That's a basic level of emotional support on a one-to-one basis. We have Zoom calls twice a week in the evening where people can join from home.

~ We have ~ a general night and we also have a games night. The games night is nice because it can be a nice distraction from the treatment. We also provide advocacy so we can help Deaf patients deal with any issues with the hospital, for example, getting interpreters booked, if anything needs clarifying, help with their benefits and other finances, and also end of life care, so dealing with social services and... signposting people to suitable resources that will be able to help them and obviously plan, you know, how to get ready for the end of their life. We do a lot of translation about cancer to help people understand the jargon terms that are involved. It's very common for Deaf people to have a reading age that's much lower than perhaps hearing people, so it's not easy for them to access written information. Their literacy can be quite poor, so we break it down. I mean, even hearing people don't understand some of the big words that are involved in cancer treatment, but we help break down those barriers for Deaf people. And we help them understand what their cancer is, what it means for them, what to expect. ~

Obviously, each person's cancer journey is going to be different and individual to that person. So there's general information that you can give them that means this may or may not happen for you. But we always sort of make sure they go to their medical team to get the medical information. But we try and make sure that they've got a good understanding of what's happening for them. Other ways that we support them, they can contact us for support if they want. We are basically there for them on a national basis. They can contact us by text, through video call, through email. We're more than happy for those kind of contacts.

Carly (24:20)

Can I ask, do you know of any other similar projects around the UK or are you the only one supporting Deaf people with cancer that you know of?

Claire (through interpreter) (24:32)

We found that there are some local services but they're quite often short-term projects that just are funded for a short period of time and then stop. We already have been going for eight years and we are ongoing so in that sense I think we are unique.

Paul (24:47)

Wow. And Gillian, if I can ask you, when did you get involved with the project and how has it helped you?

Claire (through interpreter) (25:02)

Originally Gillian contacted me through a member of my staff who has been out and about in the Deaf community and met Gillian and thought I should probably contact her to see if she'd be interested in support to find out what needs she had and I was able to signpost her to one of my staff because we have an advocacy officer and that's what she needed. We also have a volunteer that Gillian is able to offload to for that kind of emotional support one-to-one from another Deaf person. I forgot to mention actually earlier we've got a fantastic group of trained volunteers

who are matched one-to-one with our Deaf ~ patients and give them that kind of emotional support. ~ Gillian says, need to tell me about the games night on Zoom on Thursday. I need to have a go at that. I've not joined just yet.

Paul (25:56)

That sounds like a great idea. And Claire, could I ask you, in your experience, what you've seen, what are some of the most common barriers that Deaf people face in the cancer care settings? We've heard some of Gillian's experiences, and I wonder if he could tell us a bit more.

Claire (through interpreter) (26:19)

I mean Gillian's story is really one of the biggest examples of communication breakdown. So the issue was not having access to interpreters, not having letters translated properly into BSL so she couldn't understand what was happening to her. So those are our two biggest issues. Another issue is access to resources to support them on the cancer journey. Some people have to stop work, to undergo treatment and then there's financial worries.

Some of them keep working because they feel they have to and it's like, no, you could have access to resources, ~ for example, PIP ~ or some kind of social care. There are resources out there for people and Deaf people are often not aware of that. Another issue is isolation. That's huge because if you haven't got the support, you can feel very lonely.

A lot of hearing people find there are local cancer support groups somewhere very near to them and that isn't suitable for Deaf people because of the language barrier. So that's why our Deaf Cancer Support Project, that's what we're here for, is to offer that support in their own language. So I say those four are the biggest issues.

Paul (27:33)

And in terms of, ~ from a practical point of view, from the environment in a healthcare setting, what would be helpful for Deaf people coming into appointments and that kind of thing?

Claire (through interpreter) (27:54)

Right, a tip for you, if a Deaf person has come with an interpreter, ~ often we know that there's quite a lot of waiting time for consultations, we know doctors need to take their time and everything. What I would say is sometimes the waiting time is very long and by the time you're in, you could wait two or three hours and then you sort of say, ~ Am I next? They yes, you're about third on the list. And I'm like, yes, but I've got my interpreter here. So a tip is to try and jump the queue a little bit to make the best use of the interpreter's time. Because if you don't do that, the interpreter might have to leave for their next appointment and then the Deaf person has not had an interpreter even when one's been booked. So yeah, if you can, when you are making your list, can you get the Deaf person higher up the list so there's more chance that you are gonna be on time? I know it's not nice, because it's not fair on other people, but the interpreter is there for the benefit of the Deaf patient and so their time needs to be used wisely.

Plus, when you do call out a Deaf person's name please make sure that when the Deaf person comes to reception, they normally will say, I'm Deaf. Can the receptionist let the nurse know that we've got a Deaf patient in so that people are aware? Because sometimes the name gets called out and they might repeat it once or twice and then disappear, assuming the Deaf person hasn't even turned up. [That's happened to me, says Gillian. I've waited over an hour and a half

Gillian (through interpreter) (29:22)

That’s happened to me.

Claire (through interpreter) (29:28)

So please, visually check the waiting room. If you know there's a Deaf patient, make sure, call the name, make sure you've got somebody's eye contact. They might be on their phone texting and not responding to their name because they haven't heard you call it. So don't assume someone hasn't turned up. I guess it's common sense, but just some tips.

Gillian (through interpreter) (29:47)

I like it, the ones where they've got your name that come up on a screen.

Claire (through interpreter) (29:53)

Yes, some hospitals do have that in the waiting room, either a number or the name. But it does very much depend on the hospital.

Any appointments ~ of a cancer diagnosis, consider the interpreter's wellbeing as well. A lot of Deaf people would prefer to have the same interpreter all the way through, which is fine, but it's better to actually have a pool of perhaps two or three interpreters to support that patient and take it in turns, because you've got to consider the wellbeing and mental wellbeing of the interpreters as well. That's very important.

Carly (30:27)

Yeah, it's such a great tip, but it's so simple. And actually, I think that would be so helpful for people listening to this episode. Definitely.

Paul (30:38)

And Claire, you mentioned ~ leaflets into BSL earlier on in the conversation. And I'm just wondering ~ what turns a leaflet or a verbal explanation into something more user friendly for a Deaf person?

Claire (through interpreter) (31:05)

Right, ~ in terms of information access in the consultation we always recommend an interpreter. Now I understand as we've said that time, you know, it can take a lot of time but in terms of explaining what's coming next in the procedure, ~ what's going to happen whether it's a biopsy or chemotherapy, quite often what happens is you get given a leaflet about that to save time in the consultation. That's where another barrier is there if it's in English. So ~ If a doctor's saying, this means you'll need to do X, Y and Z, sometimes it's helpful for the interpreter to sort of get that information and then they've got a bit of background knowledge so that then they come out of the appointment and the interpreter can maybe translate what's in the leaflet. ~

But in terms of your own materials, if you could change them to be less wordy, include many more visual pictures, if you can have a signed video recorded, of what the procedure is going to be or what that leaflet is talking about. I mean, that's ideal. Just a short video clip in BSL, ~ maybe with animations or somehow showing what the scan is going to look like, for example, what the equipment will look like so that the Deaf person knows what to expect before they attend that next appointment rather than turning up and going panicking because they don't know what is going to happen. So it's really important that they have access to the information of what to expect next time, that's crucial.

A lot of Deaf people who get in touch with us are often saying, what does this word and that word mean? There's a lot of that kind of terminology in these letters. And so we, yes, we break it down and we explain what it means. There was a case of somebody who was diagnosed with a blood cancer. They went to hospital for a treatment. They assumed it was for a kidney infection. They didn't even know it was chemotherapy. There was a real communication breakdown there. I mean, this person luckily got through it. But yes, it's in terms of not understanding what that jargon meant, so if it could be explained in simple terms, people would know why they were in hospital.

Paul (33:10)

Thank you. And I was shocked to hear from Gillian how she was given the tablets and kind of sent away without any kind of explanation. I mean, in terms of the barriers, what implications does this have for ~ people's experience and outcomes?

Claire (through interpreter) (33:35)

It can affect the outcome, absolutely, because if they're not getting that information and no one explained why it's important to take those tablets and what they are for, that's an issue. It would be helpful if someone was to have sat down and explained that tablet is for this, that tablet is for this reason, so that then, you know, when they go and have the chemotherapy, they know what that bag of tablets is for, rather than just be given them. Presumably the nurse might have said something and thought they'd explained it, but Gillian had no access to that information at all and that is no good. I'm sure it's the same for hearing people too. ~ You know, not all of us ~ have in-depth knowledge about medication and tablets and what they all might be for. So I think it would be nice if the whole system was more human. We are all human and we all have a right to accessible information in a way that suits us. And it doesn't need to be technical, it can be broken down.

I ask people to work together, check that people are okay, check they understand it, tweak it as appropriate to support that particular patient in front of you. We all know that going through cancer is not easy for anyone. It's a tough journey. And so we all need that support to get through it. So what Deaf people need is information in a way they can understand it and process it and understand what's happening to them. So as they go through their journey, then they've got that reassurance that they understand what's going on. Too many Deaf people are panicking and anxious, much more anxious than they need to be because they literally don't understand what's happening to them. And obviously not just Deaf people, hearing people as well, when they are on a cancer journey, you know, they need to be supported every step of the way.

Paul (35:22)

Thank you. And we're privileged to meet Gillian today to hear her story. But Claire, Could you tell us kind of the scale in terms of the amount of people that you're helping as part of the project?

Claire (through interpreter) (35:38)

I've just done a little bit of research before coming here. I am certainly aware we've got over... there's over 121,000 Deaf people in the UK. 87,000 of them are BSL users. Currently we support around 135 people. Those are those who know about our service. We feel there are many people out there who probably don't know about our service, who are not getting appropriate support but we are there for them if they could find us.

Paul (36:11)

Thank you.

Carly (36:12)

And I think as well, this podcast will show how important your project is. So hopefully more people will know about it and to refer people on to it.

So Gillian you shared that for such a long time you didn't have an interpreter and I wanted to know maybe Claire you might be able to talk a bit about this. What was the reason that or why didn't Gillian have an interpreter that she very well needed to have? Can you say any more about that?

Claire (through interpreter) (36:51)

That is very common all over the UK, certainly not just Gillian, a lot of Deaf people. And now it should have a flag on their records that there's a Deaf person that needs an interpreter. It all starts with the GP and then the GP referral goes from there. Now the GP obviously knows that Gillian's Deaf and should have it on their referral to book an interpreter.

But for further investigations, that flag needs to get passed on and so often it doesn't get passed on to the next part of the system. you know, the hospital does have a duty to book an interpreter, but if there's nothing on the record in the referral that gets made, they won't know that initially. So that needs changing, that initial system passing on the information. In terms of booking interpreters, they're often booked via agencies. The hospital will probably have a contract with a particular agency.

Reception should book an interpreter. What then often happens is a very grey area because they often do not inform the patient that there's an interpreter has been booked, which means on the day as a Deaf person you're turning up going, where's the interpreter? So you go to reception and they say, ~ we booked one, but the interpreter hasn't turned up maybe.

Gillian (through interpreter) (38:06)

So often it's through phone calls, which Deaf people can't do.

Claire (through interpreter) (38:11)

The agency should inform the hospital saying we've booked an interpreter, this is the name of the interpreter. So if that happened and you knew who it was going to be, on the day when the interpreter comes, you know, they're a perfect match for the patient and the patient knows about it. Going back to what I was talking about, a grey area, quite often reception have booked, they've informed the agency, the agency have informed reception at the department, but the department have not informed the Deaf person.

So Deaf people have that extra worry. The reception says, I'll book an interpreter for next time, but you never know until you turn up to your next appointment. It feels like it's a 50-50. Will the interpreter actually be there? So that's an area I'd like to polish up, even with the hospitals that do book interpreters. We'd like to know, thank you. A further issue is ~ registered qualified interpreters. There are not enough. There's only one interpreter for every 60 Deaf people in the UK as I say, the demand is high. if you want to guarantee an interpreter, you really need to be looking to try and book at least two weeks in advance. So try and get those bookings made.

Now, for example, if someone's diagnosed with cancer, you do know there are these appointments that are gonna be coming up. So if you could book at that point in advance, that flow of appointments, then it's sorted. I do understand there's sometimes there's cancellations or things change, but if you can try and get some continuity, then you've always got an interpreter there and you haven't got the same number of breakdowns where interpreters don't turn up or what have you. Because that can really affect the outcome if you haven't had book interpreters and understanding through the course of treatment.

Gillian (through interpreter) (39:59)

Yeah so I need to get ~ regular bookings for my treatment and they quite often say, sorry we don't have enough staff in terms of we don't have enough interpreters. So that's an issue as well. You you can't always get an interpreter when you need them.

Claire (through interpreter) (40:17)

These are some of the challenges that we face. We aren't on an equal footing. We certainly don't feel that we are. But there are little things that we can do to compound the problem. And if they all add up, that can be a real issue for us. So we just have to sort of get through as best we can.

Gillian (through interpreter) (40:36)

Sometimes I have not had an interpreter even more recently. And when I couldn't have a face-to-face interpreter, I've had a remote interpreter. And sometimes that's okay. Sometimes it's not great because if the Wi-Fi isn't great, then obviously you can imagine the interpreter is not smooth to watch. What I'd rather have is to have an interpreter there in real life. I prefer that to a remote interpreter because sometimes it's difficult when the remote interpreter is there. ~ the other nice thing about a real-life interpreter is that you can have a chat in the waiting room while you're waiting and that kind of thing. It's much more human.

Claire (through interpreter) (41:12)

That is a potential barrier, the increased use of remote interpreters because some hospitals do not have very good Wi-Fi so the interpreter is either juddery, know, the Deaf person can't see them clearly. ~ Sign language is a 3D visual language, you can see that today. ~ And so on a 2D screen, information can be missed and you haven't quite got that same connection. ~ Sometimes it can work, don't get me wrong, but it sometimes doesn't work. And health settings, really, you do ideally need a face-to-face interpreter. Some of the information you're giving is important, life-saving information, and it needs to be given correctly.

Paul (41:57)

Claire, we've heard examples when interpreters are not present at an appointment. What could health professionals be doing differently to make it a better experience for a Deaf person if an interpreter isn't present?

Claire (through interpreter) (42:19)

It's difficult to answer that because it's going to depend on the hospital and what their procedures are. What we'd like to see is if the doctor has got the capacity to, I guess, say, you know, let's limit this appointment to the very important information or maybe try and get a video interpreter. But, you know, really, as we've said earlier, the quality hasn't been that good always when there's been video interpreters.

If it's impossible to get a video interpreter, sometimes it might be a case of re-booking the appointment So saying to reception, you know, we need to book this appointment and book an interpreter. What my major thing you need to understand is never ever ask a family member to interpret at an appointment like that because we have got a right to an impartial full translation and that's what you need an interpreter for. If you involve family, they quite often miss stuff out, they don't give the full information and it isn't fair. So my advice to doctors or health professionals is if they know the system well and can get a work around, that's great. But if you can't have an interpreter and it is very important information, try and rebook the appointment as soon as possible and book an interpreter for that appointment.

Carly (43:46)

Thank you. Can we move on just slightly to talk about a part of your project, Claire, a more recent part of your project around supporting Deaf people with cancer in palliative and end of life care settings. Could you tell us a bit more about that work?

Claire (44:10)

Yes, well we have seen evidence that more and more Deaf people are being diagnosed late and that means their outcome are less likely to be positive. It's more likely that they're going to pass away sooner rather than later and we want to create something to support them during that last part of their journey. So we're making video clips and we're signposting to resources to help people plan their end-of-life care.

And also, as you'll be aware, that covers the legal things they need to do, the provision that social services can make to get their house ready, rather than doing that at the last minute. Tying up loose ends, tying things up while they have got time, again, not leaving things to the last minute. And trying to give them the tools so that they know, like for the hospice staff, for example, any communication changes that need to be made in advance so that as the person comes to their end of life, we found that their communication style can change. So that language of BSL, it can be much more tiring or they physically can't do that. They can't produce the BSL in the same way. So let family and hospice staff know that they might need visual methods where they can point to pictures to check understanding. ~ I know it's really hard to face the reality that their time is coming.

Also give them reassurance that they can do as much as they can to plan hopefully what we call a good death. You know, we don't want anyone to have a bad death because that isn't nice and we give examples so you know the body seems to be marvelous doesn't it and how the body itself prepares for death so the body does kind of switch things off in a certain order. ~ So you know if they don't want to eat anymore just say that is the body's way of preparing for death, your body is starting to shut down. ~ It's not necessarily going to be painful, but it would be painful if you tried to force that person to eat. So it's education for the person and their family of things like that. Also making their wishes known, so making sure the person is clear about what they want. So that towards the end of your life when you might not be clear, you know, it's harder for you to explain.

While you are still able to think about this, you know, what you want for the celebration of your life or what have you. So there's lots of little bits that come into this. A lot of Deaf people do not realise that there's a lot that they could do for end of life care. There's a lot to think about. ~ So we're going to create almost like a checklist for them to help them sort things out so they're ready and support them to let the people around them the person know as well and also be aware so that they can make sure that person has the best send-off as possible.

Carly (47:06)

Yeah, wow, that sounds amazing. It sounds very important, that work that you're doing.

Claire (through interpreter) (47:13)

Yes, definitely is.

Carly (47:19)

I wanted to come back to you, Gillian, if that's okay. And I wanted to ask you about thinking about your experience over the last 10 years through your cancer ~ diagnosis. Along that time, and I'm thinking about people who are listening, what are some of the things, and they can be small, that would have made a really big difference to you in a good way? Could you share any examples?

Gillian (through interpreter) (48:08)

I wish I'd had interpreters when the doctor was explaining things to me. Sometimes when I would get to the appointment, I'd say, hello, and then say I'm Deaf. And then you could see the doctor was thrown by that. They weren't expecting me to be Deaf. So I wish they were aware ~ that there were a lot of Deaf people out there. So, and if there is a Deaf patient, they should have an interpreter there because I've missed out on a lot. So, yes, I wish the doctors, you know, better understood the need to have an interpreter. And I hope that starts from now and continues into the future because I don't want other people to have to suffer like I did.

Claire (through interpreter) (48:56)

Maybe extra time in a consultation. Sometimes ~ the doctors have only got 10 or 20 minutes, then you have to be out and they don't have enough time.

Gillian (through interpreter) (49:06)

I've had five or 10 minute appointments. So very, very brief appointments. I've never been able to have longer appointments. You're right. That would help. Yeah. So they don't explain enough. So I'll get home and I think, gosh, what was I supposed to do? I don't know.

Claire (through interpreter) (49:24)

In terms of ~ using BSL, we like to say it takes extra time. It can take a little bit of extra time to explain things clearly in BSL. So Deaf people could have additional time at their appointments.

Carly (49:35)

Yeah, yeah, five minutes isn't a long time at all, it? And am I right, Gillian, that now you have better access to an interpreter compared to when you were first diagnosed? Is that right?

Gillian (through interpreter) (49:49)

It's much better, yes. It's much better now. But the first time when I got there, the doctor was on the holiday that I normally saw and the other doctor, it had to be cancelled. And then the one appointment after that was somebody that it was very, very difficult to lip read them and I could see my daughter was getting quite agitated and we had to cancel that one as well. And then the third one, my daughter came back and said, well where's the interpreter?

So she got angry and shouted at reception and since then I've now had interpreters at all of the appointments so it's been good. I'm happy now. ~ I can't do it without an interpreter.

Carly (50:35)

Yeah, absolutely.

Paul (50:38)

As we bring the episode to a close, we have our final three question feature. Claire, I'll start with you. If you could go back in time to the start of the project, what piece of advice would you give yourself?

Claire (through interpreter) (50:56)

You'll be fine. Make the project a success. ~ Because obviously I've got experience of going through cancer myself and then I became a volunteer, then a member of staff and now a manager all over a very short period of time, but it's been amazing what I've achieved. So I just want to continue supporting the Deaf or Deaf cancer patients on their cancer journey as best as I can. So what I would say to myself back in that first early stages, you'll be fine.

Paul (51:34)

Thank you, Claire. And Gillian, if you could go back in time to when you were first diagnosed, what advice would you give yourself?

Gillian (through interpreter) (51:46)

I wish an interpreter had been there, I would have been fine. I would have been fine with an interpreter there.

Paul (51:55)

Thank you. And the second question, again, Claire, I'll start with you. What change would you like to see to improve the lives of people living with cancer?

Claire (through interpreter) (52:12)

Stop inequality. Yeah, in healthcare.

Paul (52:18)

Thank you. And Gillian, what change would you like to see for people living with cancer?

Gillian (through interpreter) (52:32)

They must have interpreters, please. Everybody needs an interpreter. ~ So they need that so they know what's going on for them.

Claire (through interpreter) (52:42)

To add to that... Yes, Deaf people need interpreters, but also ask them for their communication preference. So there's interpreters that use sign language, and then there are different people that need cue to speech or different needs. So ask the patient about their communication needs and then provide that. Don't assume that all Deaf people will be BSL users.

Paul (53:09)

And the last question, Claire will start with you. What would you like our audience to take away from this episode?

Claire (through interpreter) (53:23)

What you can do to make a change, reasonable adjustments, that's all we ask to help our journey through our healthcare journey and make it better.

Gillian (through interpreter) (53:32)

I agree with her.

Carly (53:36)

Thank you. Thank you for adding that. And I was going to ask, is there anything from either you, Claire, or you, Gillian, that you did want to also talk about that we haven't already talked about?

Claire (through interpreter) (53:46)

I would say, you know, we're all human beings. And I know it's very, you know, frustrating and scary and anxious time for the Deaf patient. So please be understanding that they are going through their personal challenges and facing barriers. So if you can be kind to them and help them and do as much as you can to help understanding, they're less likely, you know, not just find it difficult and leave the room. That would really help in the long run, just the more understanding you can show people.

Carly (54:20)

Yeah, I think that's a lovely and really brilliant advice.

Paul (54:24)

Today we've heard how small changes like booking qualified BSL interpreters and adapting environments can make a huge difference. Before I wrap up the episode, I just want to say a thanks to our guests, Claire and Gillian, for sharing their experiences and insights so openly today. Your stories and expertise has given us all a deeper understanding of the challenges faced by Deaf people affected by cancer and the practical steps we can make to make care more inclusive.

I also want to say a special thank you to our interpreter, Rebecca, whose skills and presence has made this conversation accessible for everyone. And it's a reminder how vital good communication is, not just for our podcast, but every part of the cancer care.

If you'd like to find out more or access resources mentioned in today's episode, check our show notes for links and further information. And if you have any feedback or questions, we'd love to hear from you. Thank you again, everyone, for listening. Let's keep working together. And thank you, Claire and Gillian.

(Outro music)