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# Martine Monksfield: A Deaf Mum's maternity experience

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*By Martine Monksfield*

It was quite the shock when the sonographer told me I was expecting twins at my 12 week scan in January 2021. Married to a Deaf man, I have a 7 and 5 year old (hearing) at home already affectionately called GingerNut 1 and GingerNut 2, and the pregnancies with them both were tough on me with severe sickness and intrahepatic cholestasis of pregnancy (ICP), also known as obstetric cholestasis (OC)[1]. We always wanted more children but we were very conscious of the toll of pregnancy on me. The ironythat the terrible pandemic and the restrictions that came with itmeant we figured it was a good time to go for another. The flexibility of working from home would allow me the space to rest and recover as my role as an advisory Teacher of the Deaf involves local travel to several family homes, nurseries, schools and colleges.



I am very glad we did this as I knew I was pregnant in week 4 when I started throwing up on the school run with my older two. It deteriorated from there, to the point where I was diagnosed with hyperemesis gravidarum (HG). In early January 2021, before the scan I went to my first booking appointment in tears, having been in a vicious cycle between my bed and the toilet for all of December 2020. Thank goodness for a new medication that was prescribed for me, a mixture of antihistamine and Vitamin B6, designed for severe sickness and vomiting in pregnancy, which has reduced my symptoms somewhat to a level where I can function more normally. My boss was incredibly understanding too when I returned from two weeks sick leave in January while I recovered and adjusted to the medication, as it made me very drowsy initially.

Communication at the 12-week scan was smooth, despite the sonographer and his assistant wearing medical masks. The shock of twins meant I had several questions which were all answered. This was possible due to the use of a British Sign Language (BSL) interpreter, which I hadn't even requested as I had lost faith in the NHS to secure them for me from previous experiences. I'd request one, but none were ever booked. It was always claimed 'no one was available' – something many of my Deaf friends and I heard several times when we shared experiences. I do question whether this is standard practice for all Deaf Mums-to-be, as not every Deaf person uses British Sign Language. How did they know I used BSL?

Looking back, I think there was no system implemented to secure BSL interpreters and admin staff had no idea one was needed or did not know how to book one. I know from other Deaf people's experiences that this lack of BSL access rings true in other departments across the NHS[2]. One worrying example was when a daughter had to interpret when her father was receiving a terminal cancer diagnosis[3]. There is a real lack of funding for BSL access, lack of Deaf awareness and a very poor infrastructure. It seems to be a bit of a postcode lottery. I am fortunate to have speech and am able to voice for myself, but the input of spoken English to my ears is never a guarantee despite the advances in technology (cochlear implants, hearing aids, bone-anchored hearing aids, etc.), so the use of BSL interpreters in my life relieves me of that burden and ensures communication is smooth. It means I have more energy to listen when BSL interpreters are not available (not that I would want one attached to my hip anyway!). While the diversity of its staff is one of the strengths of the NHS, it can add to the challenge for Deaf parents, and there were times where I struggled to follow/understand unfamiliar accents. It would take me a good 10 minutes to adjust, with lots of repetitions and some writing down of key words I couldn't understand despite

'hearing' them. This is one reason why continuity of carer, seeing the same midwife on every visit, would be really helpful to Deaf women.

There were some positives in previous pregnancies; I was often texted with the results of my blood tests (especially for ICP) and also for appointment notifications and reminders (generic now for all appointments), which really helped, but there were the odd phone calls when I would run about looking for the nearest hearing person in case it was maternity needing to get hold of me. I didn't have a BSL interpreter during my first vaginal birth, nor for my c-section when I had my second baby, but as it went as well as could be with my Deaf husband for communication support, I just accepted early on that I would be going without.

Looking back, I wish I had had a BSL interpreter with my first pregnancy as it only transpired during my second pregnancy that I had had ICP with my first and that this was never communicated to me. I am certain there was an air of restricted communication with me because of my deafness and everything was very 'basic' in terms of what was relayed to me. This can be demoralising given I am a very capable independent Mum with a postgraduate education. I would have appreciated the written information, even printouts, but I suspect that this is time-consuming for them. It also would have meant I would have read it all and had questions, for which I would have needed a BSL interpreter. I am not sure they had the facilities to organise this then. Written information is not accessible to all Deaf mums as not everyone has a good level of literacy skills due to education not being accessible or because of language deprivation in the early years (signed or spoken).

I remember some midwives in the post labour ward after my first, asking how I was going to be alerted to a baby waking for a feed and if I had someone hearing at home with me. This was interesting, the fact they immediately assumed I needed a carer. I explained I had a baby monitor alarm which would vibrate my pager when the baby was crying. In the olden days without the use of assistive technologies I was regaled with stories of Deaf Mums attaching a string to their baby's wrist and to their own wrist to alert them when babies were crying at night (usually with arms akimbo!). With my first baby in the post labour ward, the pager would alert me to every other baby crying at night, not just my own. For this reason I came out of the hospital quite tired and relieved to be home. When I had my second, I asked for a private room for that reason, and thankfully there was space for me to have one. I think this needs to be standard for all Deaf Mums, ensuring they have the assistive technology to alert them to their crying baby.

It cannot be assumed that all Deaf Mums are even aware that this technology exists. There are no specialised health visitors for deaf mums. There used to be specialised deaf social workers, but this has gone now and deaf people are in the general sensory support team. My experience with them is that they don't know what technology is out there for deaf people. We have a Deaf Mummies and Friends group on Facebook where we share tips, advice and guidance for things like this[4]. The big issue at the moment is the discontinuation of video cameras with monitors that vibrate! Many parents are using two systems, one where there is an audio system with a vibrating pager, and a video camera with a monitor that

doesn't vibrate. Not all deaf mums get information or access to this sort of assistive technology for a myriad of reasons linked to education.



*GingerNut 1 born Jan 2015 by vaginal delivery, then in neonatal care for 24 hours as a precaution, as his meconium was in my waters.*



*GingerNut 1 was 8lb 11oz. I remained in hospital with him for 5 days due to my liver function being abnormal (which we realised in the 2nd pregnancy was ICP/OC, but no professional communicated this to me at the time!)*



*GingerNut 2 born by c-section due to being breech and ICP/OC, needing to be delivered before 37 weeks. Born at 36 + 5, this one was 8lb!*

I was very grateful that, for whatever reason, my experience as a Deaf woman has greatly improved since then. I have not had to request, check or worry if a BSL interpreter is going to be booked for all my maternity appointments, bar one, which was at the last minute for a scan and no one was available (I believed that this time!). They wanted me to wait until someone was available, but it was coming up to 50 minutes past my appointment time and I was starting to feel a little unwell (thanks HG!). In this instance, they were happy to remove their masks with social distancing in the room after the scan to go through the process and what they had seen. This massively removed the burden on me to ensure accessible communication during maternity appointments. My other Deaf friends who are also expecting a baby have reported the same – BSL interpreters are now being regularly booked for their maternity appointments.

My best friend, also Deaf and who has just had her 3rd baby, trained to be a midwife before stopping after her 2nd year for personal reasons. She found the interviewing process arduous and discriminating. My friend was told in no uncertain terms that she would have to be able to meet one of the components to pass – the Pinard test, where you listen to the baby's heartbeat.



*Pinard*



*Sonic aid*

*Image source*

*Image source*

Apparently, this isn't actually commonly used anymore (not that she knew that at the time). She sought out ways to get round this, and discovered there was an amplified stethoscope you could order from

America for those with deafness in order to listen to heartbeats. The stress and pressure on her during the training process on this one component caused several sleepless nights with no support from senior midwives for reasonable adjustments. Other trainees and registered midwives (hearing) would also tell her they could barely hear the heartbeat on the Pinard. She found out that the Sonic Aid was used to listen to the baby's heartbeat and was very loud, so she was able to use this instead.

It seemed to her that the components set by the NMC (Nursing and Midwifery Council) did not consider any reasonable adjustments for trainee midwives with disabilities, and it was only through the support of other trainees and registered midwives who suggested reasonable adjustments that she was able to pass the Pinard test with a note to say she passed this with the Sonic Aid. To this day she remains perplexed as to why she was accepted on the course if the interviewers were very reserved about her passing this particular component during the interview. She was asked how she was going to communicate with mothers-to-be if they had her back turned to them. Fairly straightforward solution: ask them to look at her when they spoke, something Deaf people do daily. It was a real shame they didn't see the advantage of having a Deaf midwife in the profession, as not all mothers-to-be are hearing and Deaf people are more likely to know how to find solutions for communication as they are used to doing it their whole lives. This knowledge, skill and experience can be shared with the midwife profession which can only benefit the NHS in the long-term when learning how to communicate with a range of Deaf mothers; from those who use BSL to those who don't.




One thing that definitely needs improvement is the way in which Deaf Mums-to-be are contacted post birth – either by the midwife or health visitors to their homes. Often, visiting healthcare professionals don't know that the Mum-to-be is Deaf and make phone calls, which will frequently go unanswered if there is no hearing person nearby to take them. I know this because my best friend (mentioned above) recently gave birth and there were a few missed calls before the midwife just turned up at the door. Thankfully, we were at home! The handover process between the labour ward/post-labour ward and the post-birth teams needs to ensure this information is included and that it is made obvious, and that midwives and health visitors know how to text and also how to book BSL interpreters for home visits should one be needed. I've been fortunate that in my area, my mother-in-law was a manager of the health

visiting team, so she is always on the lookout for this information and knows how to text if mums are deaf and that she should book BSL interpreters for Deaf Mums in the area. She knows this because her son and her daughter-in-law are deaf, and if she isn't sure, she is able to ask us for advice. What about those who don't have this kind of network?



*My best friend and mel, me at 24 weeks and her at 39+5, in between her irregular contractions – she gave birth 6 hours later!*

I've been fortunate to have a Sign Live account. Sign Live is a BSL video interpreting agency that I can use on my phone, anytime and anywhere. This is paid for through Access to Work for my job[5], but sometimes I will use it elsewhere where appropriate. I have a special phone number that looks like a landline number but is actually connected to my mobile number. Anyone needing to speak to me to discuss something that can't be done over text message (where they would text my usual mobile number) is automatically connected to a BSL interpreter from Sign Live before being connected to me. I will answer the phone as it comes up as 'Sign Live' so I know immediately that someone is genuinely trying to get hold of me. If a typical number comes up on my mobile, I don't answer it because there are too many variables to ensure I can understand and follow a phone conversation; accents, background noise, clarity of speaker, unknown context, etc. Unfortunately, listening involves so much more than just 'hearing' for a Deaf person. Recently, maternity contacted me to talk about my Liver Function Test results as they have shown a high level of ALT (Alanine Transaminase) – 383 compared to the maximum of 35! They had to explain what I needed to do to start regular monitoring as we all suspect that this could be the onset of OC/ICP. SignLive will be especially useful if I have last-minute appointments with maternity and they cannot get hold of a BSL interpreter face-to-face[6]. I suspect I will be using this sometimes.

After every baby is born, they undergo a newborn hearing screening test before going home (or they come back in for it). Some professionals need to be aware of the language they use with regard to this: many of my Deaf friends are often told, 'Congratulations, it's good/great news, they passed!', as if being

Deaf is bad news. It's understandable to say this to hearing parents who have no experience of deafness and who would therefore find it worrying, but not all Deaf parents feel this way. We were fortunate in that we made it clear to the professional carrying out the newborn screening for our babies that we would not be upset at a referral and that we considered Deafness a cultural linguistic minority; moreover, even if the babies were hearing, they would be learning BSL anyway.

I am hoping all goes well with this twin pregnancy – there is definitely a sense from me that communication has improved this time around, but there's always room for more tweaking to make it work for all Deaf people entering maternity care. Wish me luck!

Twitter: @martinemonks

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**Author Bio:** Martine is a profoundly deaf advisory Teacher of the Deaf, uses a cochlear implant and is bilingual in British Sign Language and English.

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[1] www.aims.org.uk/journal/item/understanding-intrahepatic-cholestasis-pregnancy
[2] SignHealth, 'No money, BSL Health Access is closing': https://signhealth.org.uk/press-release/no-money-bsl-health-access-is-closing
[3] Deaf News, 'Daughter forced to interpret father's terminal cancer diagnosis in NHS communication breakdown': https://limpingchicken.com/2021/02/17/deaf-news-daughter-forced-to-interpret-fathers-terminal-cancer-diagnosis
[4] Deaf Mummies & Friends UK Facebook group: www.facebook.com/groups/761751567214726
[5] GOV.UK, 'Access to Work': www.gov.uk/access-to-work
[6] SignLive: https://signlive.co.uk