



## **A real life story: Five months in pain and not being listened to: a sister's account**

My brother Hugh was about 43 when this punishing and frustrating period of about five months occurred. Hugh is unable to speak due to a (profound) learning disability and so has very limited communication, but people who know him very well can meaningfully interpret many of his facial expressions, sounds he makes, his actions or the way he positions himself. Hugh is a really sociable chap who loves being with people, particularly those he knows and those who make the effort to interact with him. On many occasions, he is reliant on those who know him well to advocate for him – especially when what he has to 'say' is not heard. As his older sister I am his next of kin and on very many occasions, sadly, I have needed to augment his voice.

Until the time of these unfortunate circumstances, Hugh's health and general well-being had been good. Looking back, one or two of us had noticed some unusual 'communications' from Hugh some time before it became clear that something was wrong. My first concern was when a support worker brought him to visit me. When I came out to meet him at the car, he wasn't his usual happy, excited self at seeing me and was reluctant to get out of the car. Chatting to the member of staff we assumed he was maybe just a bit stiff after the two hour car journey, which he would normally love. She mentioned that on the journey he was quieter than normal and at one point she had seen an unusual expression on his face – as if he was about to burst into tears. He has not cried since being a few months old, so this wasn't something we had seen before. He doesn't shout out or make any sounds or obvious signs when he is hurt. His communication difficulties meant he was unable to tell us what was wrong. However, once he was out of the car and moving about again he seemed to be back to normal and we enjoyed a long walk later in the day.

Several days later we were concerned that something was really not right. There was a sudden unexplained difference in Hugh's communications and his behaviour, noticed by all who knew him well – family, friends, support workers from his home and his day centre. The way he was communicating and the frequency, told us he needed us to respond. He altered some of his usual sounds and actions. He has a repetitive action where he constantly flicks the fingers and thumbs of both hands together, usually with his hands about waist height – this seems to make him feel secure. When he is anxious or upset, as he appeared to be then, he repeats this routine, but right up near his chest or face; his hands and arms are held tightly close to his body. He also makes a particular sound when he needs or wants something. At this time, he changed



the strength and volume of these vocalisations to communicate insistence or urgency. These nuances are why you need to know Hugh well to interpret what (and why) he is trying to communicate.

Several of us suspected it looked possibly like back pain from what we saw him doing and from our own experience of back problems. He showed unusual postures, a clear reluctance to sit, he radically changed his sleep position, his attention span was much shorter than usual and he showed a general reluctance to do anything for long ... even eat! Staff from both settings pooled their observations, using a Mencap resource called '*I'm talking...are you listening?*' This framework enabled us jointly to see what changes were noticed in Hugh's communications and behaviour, but also to try and identify anything in his life that may be causing these (eg staff changes, illness, bereavement, moving home etc). There was agreement from all that there were no apparent 'events' to changes to Hugh's life or routines and the unusual behaviour was evident both at home and in his day centre.

Staff took him to see his GP straight away. The doctors at this surgery are very good, always giving time to Hugh and his supporters. However, we know that Hugh is always 'very obliging' at health appointments and will let practitioners do anything to him whilst keeping a smile on his face! When having blood taken or vaccinations, the only outward response to the needle is a slight change to his breathing and muscle tone – undetected by most people who aren't looking for this. It wasn't too surprising then that the doctor's check over found no obvious problems, so there was no diagnosis. The GP suggested trying paracetamol to ease Hugh's 'apparent discomfort' and to return if needed.

These GP visits continued inconclusively for some weeks; blood tests ruled out other medical problems. Following staff persistence a referral for a physiotherapy assessment was made by the GP. I suggested Hugh see an osteopath as I had successful experience with them, but staff at his home wanted to follow NHS services. The physiotherapy assessment took a few weeks to take place but again offered no conclusion as Hugh showed no reflexes to pain. Staff mentioned to the physiotherapist that we were considering seeing an osteopath. The manager was told that if we did this Hugh would be discharged from any future NHS treatment for this problem.

However in this time, Hugh was displaying to those who knew him well through his communications and other behaviour that he was in considerable discomfort and pain. His behaviour became more extreme in every way. He had lost his normally very healthy appetite and showed a very significant weight



loss. He was refusing to lift a cup or a fork to his mouth without lots of persuasion. He couldn't relax at all and his whole body was constantly tense; he wouldn't sit down but just kept 'on the move'. He was exhausted yet he was not sleeping. He looked grey and haggard. His usual cheery and placid personality had changed to become very tense and irritable. It was so upsetting to see. Medication to relieve pain worked for short spells, but you could see when the next dose was due as Hugh became tense and clammy. Hugh began grabbing and pulling at everyone – not a usual behaviour from him. I saw this as him 'asking for help'. Unfortunately not everyone saw this in such a positive light. At this point there was no diagnosis or anything to acknowledge a reason for his change in behaviour. Some staff felt he was just 'attention seeking' and that we should accept the verdict of the doctors and physio. What we needed to do was to deal with this 'challenging behaviour'. I found this even more upsetting.

By this time Hugh had started to limp and was reluctant to walk far. He would not sit at all, preferring to lie on the floor. He became incontinent as he wouldn't tolerate sitting on the toilet - he would get up from toilet and 'go' standing up. In fact he fell during one visit to the toilet in his urgency to stand up. I accompanied Hugh on a visit to the GP following this fall. The doctor diagnosed a cracked rib, mainly by listening to Hugh's breathing rather than his response to the examination, but still nothing about the main cause of it all. I tried to explain that Hugh did not have all the usual reflexes or responses to pain that you or I would show and that he wouldn't necessarily resist movement if in pain as we would. I described some of the, by now, many ways he was behaving that we interpreted as his way to communicate pain he was experiencing or his responses to try and avoid more pain. The doctor disagreed and felt sure he wouldn't have been able to carry out his examination if Hugh had any injury.

It was with my persistence that I convinced the home manager to let Hugh see an osteopath. I was recommended a local osteopath and contacted him to explain Hugh's situation – the history of the past five months. I was there when he visited Hugh at home, as were staff who knew Hugh very well. Within ten minutes of meeting Hugh and hearing about how he was behaving and moving, the osteopath felt ready to examine Hugh. He did this in Hugh's own room to help him feel more at ease and with me to help him interpret Hugh's communication. I had told the osteopath that Hugh may not show when he is in pain. Within minutes the osteopath was showing us where Hugh had injured



his lower back. He had been able to feel a physical difference to the muscles supporting his spine, but he also noticed a slight curling of Hugh's lips when he touched a particular spinal disk that was protruding – *we hadn't noticed Hugh do this!* He also showed us other areas where Hugh was experiencing pain in his upper back and shoulders – this was referred pain caused by Hugh's body naturally trying to protect itself from further injury. This was why he couldn't drink or eat comfortably.

It was *SUCH* a relief for us all – that someone was listening (to us all), taking us seriously but also helping us to resolve the traumatic situation for Hugh. He told us he had been able to look beyond 'normal' reflexes and responses, following our lead about the changes in muscle tone and breathing that Hugh often uses to communicate. We were lucky to find a health practitioner who was so aware and sensitive to such tiny expressions as responses to discomfort. We had learnt from him!

The osteopath showed us some easy 'massage' type exercises to do with Hugh daily along with some other simple treatments for the inflammation. As he demonstrated these to us, we saw for the first time in months, a glimmer of a smile on Hugh's face at the relief from pain. Hugh responded really well to this treatment and would smile and make contented sounds everyday when staff helped him onto the bed for his 'massage'. When the osteopath returned to visit two weeks later, miraculously Hugh was almost back to his usual self – very mobile again and much more his chirpy self. Luckily he had not sustained any longer term damage. If this had been you or I, we could simply have described where the pain was, when it happened, what made it better or worse and a doctor at the first or maybe a subsequent visit would have been able to help us. Because Hugh could not share this with the doctor or show clearly enough to the doctors where it was most painful, they did not seem willing to take our views seriously enough. If the health practitioners had had some training about people who communicate without speech we could have worked together more effectively and ultimately, we could have saved Hugh months of pain. Thankfully he is now fighting fit.

**Hugh's sister<sup>1</sup>**

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<sup>1</sup> The names in this story have been changed to preserve anonymity