

Hearing the bad news and planning the way forward

My name is Paul Watson, and I am the father of twins, Emily and Christopher, who attend Percy Hedley lower school.

I worked in the civil service for many years, but everything in my life changed when Emily and Christopher were born extremely prematurely at 25 weeks 6 days. They were both very ill in the special care baby unit, and over the next 5 months they were in there we came very close to losing both of them many times. Their tumultuous start to life has left both children with severe disabilities, and unfortunately there has been many times both in hospital and after discharge where we have been given bad news. Most of the times we've been given bad news it hasn't been a one off ground breaking event, but a more gradual incremental process along a series of appointments and clinics and I think this would be fairly common for complex children.

The first time I was given bad news was when the maternity assessment unit called me at home to say that Claire had been transferred to the delivery suite. Her waters had broken at home on the Saturday afternoon, and after being assessed she was admitted for 48 hours observation. At 2 o'clock in the morning I received a phone call to say that Claire was feeling uncomfortable and so had been transferred to the delivery suite, and whilst Claire would like me to go in and sit with her there was no need to panic. I arrived there 40 minutes later to find people running round everywhere and Claire in the final stages of labour. Emily was born 20 minutes after I arrived, and Christopher an hour after that.

In special care the bad news came thick and fast. It soon became obvious that if we were invited round to the family room for a chat with the Dr's that it wasn't good news. When we were told that both children had had brain bleeds didn't appreciate how much of an impact it would come to have on our lives, why worry about the future when it was a real possibility that they might not live long enough for it to make a difference. We had a good relationship with the Dr's in special care and they had an open notes policy where we were encouraged to read the medical notes which were kept next to the bed.

Emily improved as she got older and bigger but Christopher remained unstable. We were invited to a multi-disciplinary meeting with a room packed full of Drs to make a plan for Christopher where the general consensus was that he would need a tracheostomy. There was an opinion by one Dr that a tracheostomy wouldn't address Christopher's stability issues, but this was shot down by the lead consultant. I bet you can guess who turned out to be right..... The problem I had was not that there was a professional difference of opinion, but that the lead consultant's reason for not paying attention to the other Dr's concern was that he was a specialist whereas she was a more general paediatrician.

When Christopher had his tracheostomy we were transferred from neonatal intensive care unit to the paediatric intensive care unit where we stayed for 7 days. Instead of the open notes policy we were used to, we were faced with open hostility when we asked to see his notes. During the middle of the night we received 2 telephone calls to say that Christopher had had a major desaturation episode. At the time we did not understand why they were calling us to say that he was displaying the symptoms which had caused him to be transferred to their unit. After this Christopher was referred for an urgent cardiac and neuro review and we did not see the lead consultant again. We couldn't be given a time when the neuro review would take place, and after taking 2 days off work to make sure I was present to receive the results from it we were told it was now not going to take place and that instead he was to be transferred back to the neonatal intensive care unit. Once back on the unit with an open notes policy we read up on the events of the last week and discovered that instead of his major desaturation episode being the same as previous episodes he had in fact had a cardiac arrest. We weren't told this when the Dr phoned to give us the bad news.

After a change of approach in his treatment Christopher became more stable and was discharged home a month later. Since then, apart from the appointment where the results of Emily's MRI showed more serious brain damage than we anticipated, there hasn't been any more monumental pieces of bad news to hear but that doesn't mean the bits we have received since then have been any less emotional for me and my wife.

The NHS is an amazing institution and without it my children wouldn't be here today, but it's also a huge behemoth of a thing beset with office politics, resource problems, and sometimes very restrictive policies. For somebody working in it, it can be very frustrating but for a parent trying to navigate it with their child it can be devastating. This summer Christopher was due to have a routine operation but it was postponed several times. There's nothing unusual in this, it happens every day and has probably happened to all parents at one time or another. The problem was that this delay then delayed a subsequent extremely stressful procedure for which delays substantially reduced its chances of being successful. Just because a Dr or other medical professional might see a piece of news as being relatively minor they shouldn't underestimate the impact it could have on a parent. It could be the straw that breaks the camel's back or have some other unintended consequences.

I think that the key to how bad news is broken and planning the way forward is the relationship the parents have with the Dr and medical team. We've had good and bad experiences with Dr's. Some Dr's have been very good and we trust them implicitly. One Dr changed Christopher's treatment on a ward round despite never meeting him before and a plan having already been made by his main consultant to ensure he didn't become unstable again, and it was then extremely difficult to get to speak to him to be able to resolve the matter. Some Dr's have been very difficult to get in touch with when new issues have come to light and so we have been left hanging and worried. One Dr has seemed to give us the answers we want to hear

rather than what the symptoms suggest. To be told before a bronchoscopy (a procedure to see what condition the airway is in) that the Dr is almost certain that the tracheostomy will be able to be removed makes it all the more difficult when the results of the operation is that there is no prospect of removal. As a one off this would be excusable, but when it happens time after time with the same Dr then your faith in that Dr is demolished. If you haven't got that faith in the Dr, then it makes it that much harder to receive any bad news from them or to make any plans.

So, what are my thoughts over the way the bad news has been broken to us?

The first week in special care I was in a complete daze, and totally detached as if it was happening to someone else. I think most parents will feel that way to some extent, and most of the important questions you have will only come to you later. Dr's need to take that into account.

You can only plan the way forward if you are fully informed. Parents go from being in charge of their child's life to being a passenger, Dr's need to take this into account and keep parents fully informed and there's probably 2 aspects to that.

On two separate occasions I've received phone calls for an update on a situation only to find out later that the situation was in fact much more serious than what I'd been led to believe on the phone. On both occasions they avoided using certain words because of the negative connotations associated with them, but because they didn't then the full message wasn't put across.

Parents need to get the bad news and any future plans from somebody who is able to answer their questions, and make them feel confident that the person who is dealing with their issue actually knows what they're talking about! There are some very complex situations out there and there are circumstances where things aren't known (Emily is undiagnosed), but one of the worst things a parent can hear is 'we don't know' but when the parents go to Google (as everyone does.....) only to find that it is a relatively known situation/condition and we wonder why the Dr didn't already know this.

Things that can seem relatively minor to the Dr might not be minor to the parents. It could be the straw that breaks the camel's back because of the build up to the situation or the knock on effect of the news. Dr's need to take this into account, although with high caseloads it can be understandable why they triage how they think a piece of news might be.

And connected to that, office politics and problems with resources are immensely irritating and upsetting for the professionals involved, but they need to remember that they go home on a night, this is our whole life.