'I got to the hospital with about two minutes to spare. I’d been up for hours. By the
time I’d left home I’d made packed lunches, got breakfast ready, got the two older
ones to school, sorted out Pip’s drugs, got him dressed, sorted out his feeds, done his
stretching and about a zillion other things. Typical morning. The bus was late and I
ended up having to run up the hill to the hospital: me, Pip in his buggy and the usual
20 tons of things you can’t leave the house without. If there was a buggy racing event
in the Olympics, then I’d win: no contest. I was almost breaking the sound barrier by
the time I got to the clinic doors. I didn’t want to be late. Amazingly the clinic was
running to time and we went in straight away. I was still getting my breath back
when I sat down with Pip on my knee. On the other side of the table, he sat there
behind Pip’s notes. And then he says, “Well, rather than look at the notes, let’s start
at the beginning. What type of birth did you have?” I sat there and simply wanted to
kill him. I had this scream inside me, it was just building and building, like a giant
angry wave. I just wanted to scream “Why haven’t you read the notes? What’s the
point of the notes if you don’t read them? What sort of respect have you got for Pip
and me if you don’t read them?” But I didn’t scream. I didn’t kill him. I just took a
breath and then I heard myself say for the millionth time “It was an emergency
section for foetal distress. Pip spent the first six weeks in intensive care ….” and I just
carried on until we got up to date. It was all in the notes. It’s always in the notes but
they always, always ask.’ (Mother)

‘You’re completely and utterly away with the fairies (after the diagnosis). You and
your other half are feeling absolutely gutted. And you’re getting letters from all and
everybody. You need to go and see this person, you need to go and see that person.
And such and such a person is coming at 2 o’clock and you’ve got somebody else
coming at 4. And your husband comes in at 6 o’clock for his tea and the person from
4 is still sat there at 6. And then your 5 o’clock’s turned up on your doorstep. By the
time 8 o’clock comes, neither of you’ve been fed, the kids are screaming their heads off
and these professionals have walked out of the door and you end up rowing with your
husband. And that carries on the next day and the next day and the next. And it goes
on like that for the first 18 months after your child’s been diagnosed, just basically
from people coming round and doing form filling.’ (Mother)

I wish the stories that these two parents are telling were unusual ones; that they
were the sorts of stories that weren’t commonplace. Yet these stories are fairly
typical of how all of us, at least some of the time, are still getting communication
and other aspects of our care wrong. Nurses and other health care professionals,
social workers and teachers are all, pretty much, dedicated to providing high
quality care, support and educational opportunities for children and their
families.

All of us know the importance of good communication not only with
children and their parents but also with each other. We know it. We talk it. But it
often goes a bit wrong. When it does go wrong it’s all too easy to blame the
professionals for not caring, for not trying and not being there for children and
their parents. It’s all too easy to find excuses like we’re too busy, it’s too hard,
we’re doing the best we can but it’s not working. We can also blame the parents
for not understanding, having unrealistic expectations and for getting the wrong
end of the stick. However, when push comes to shove we all have to accept that
we have a responsibility to try and understand how each and every child and
family we come into contact with receives individualized, effective and caring
communication and interventions from us. This is not a set of skills that can
easily be acquired; it’s not possible to learn these skills from a book or to sud-
denly have a revelation as a consequence of reading the latest theory. Developing
these skills in understanding how we communicate with individuals in a dynamic
way is truly something that is life-long learning. We need to be critically reflective
of the times we get things right and the times we get things wrong. We need to
take time to stop and notice whether or not we’re getting things wrong. Often
parents can be left feeling distressed, angry, confused, and de-valued as a result
of a communication incident that we have barely registered because it was so
‘routine’. Nothing about communication is routine for parents: everything we
say and do, or don’t say or do, is significant. Our best teachers in terms of getting
things right are not books and theories or even the best lecturers or clinicians in
the world. The best teachers, providing we take notice of them, are the children
and parents.

Reference
nursing/research/groups/children/index.htm