

All parents should read this heartfelt letter from the dad of one of our patients. He wanted us to share his experience when his baby daughter became very ill so parents can be aware of the symptoms to watch for and how important it is to follow advice from healthcare professionals.

20 January 2016 ·

Our baby girl has been diagnosed with **Pneumococcal Meningitis**. We spent from the 8th to the 15th January in Harrogate Hospital with a 1-night transfer to Leeds General Infirmary during that time for a small surgical procedure related to treatment.

Our baby has not been discharged yet, but is on Ward Leave, meaning that she is well enough to be at home but we visit the ward every day at 6am so that she can receive her daily IV infusion of broad spectrum antibiotics. She will receive 14 doses to make sure the bacteria is completely gone.

Let me say at this point that we caught the infection early enough, Our baby is doing really well and is expected to make a full recovery, with no long term effects. We've had a few days to recover now, both in terms of a week's worth of lost sleep and the horrible time we all went through in hospital during the diagnosis and treatment, which was first class.

We feel that we wanted to share a few things that we learnt during this process, not the philosophical reflections on the meaning of life stuff (of which there are plenty!) or the gory details... but a few practical and important pieces of information that we feel parents or relatives of young children would benefit from knowing.

First: We caught this infection early, but we didn't know it was meningitis. Baby had had a bit of a cold for a couple of days, we had given her infant paracetamol and she perked up a bit, the next day she wasn't so well so Mum took her to the doctors. He looked her over and as she had redness in the throat, he thought she might have a viral throat infection. "Bring her back if she doesn't improve" was his advice at the end of the consultation.

Later the next day she was most seriously out of sorts. She appeared drowsy & listless to us, she wasn't engaging with us in her usual chirpy way, she had a weak cry and was running a temperature. Infant paracetamol made no difference. We checked her over, looking for a rash (to do the "glass test" on) fearing it might be meningitis. No rash, therefore no glass test possible, therefore no meningitis, right? WRONG! Not all forms of meningitis present with a rash and pneumococcal meningitis does NOT present with a rash.

We could have decided to let her sleep, thinking that it might be a virus just running its course, but fortunately we decided that we would call the doctor and double check if this is the way that babies deal with an illness like this. That started a chain of events that lead to our baby being admitted to hospital that same night, having blood tests, having a lumbar puncture and receiving the correct medication early enough to stop the infection in its tracks and therefore avoiding the serious long term effects that 22% of sufferers experience.

So, just to emphasise my first point:

- 1) DON'T WAIT FOR A RASH to see if it's meningitis. If you feel that your child is out of sorts, CALL YOUR DOCTOR. Or in the UK, out of hours, dial 111 for the brilliant NHS 111 service.
- 2) Symptoms for meningitis present in different orders, in different ways for infants and differently for each type of meningitis, so you or your doctor can't be sure at first look. If in doubt, call your Doctor/NHS 111.

Second: When your Doc says, "Bring her back if she doesn't improve", he/she means it. "I think it might be a virus" means that this is what Baby looked like she had at the time of presentation to our Doctor. Mum and I are happy that there is no way our Doc could have diagnosed what she actually had at that stage.

Again, if your Doctor says "Bring her back if she doesn't improve", he or she really means it.

Conditions develop very quickly with infants; they can deteriorate much faster than adults generally do. Don't think that you will be judged as an over fussy first time parent. The NHS is set up to be very responsive to infants who may be unwell, as time is generally not on their side. (We called NHS 111 as our GP's surgery was closing when we called back and our appointment with the out of hours Doctor was made within 20 minutes. We were immediately referred to a paediatrician after seeing the out of hours GP. The response time could not have been better).

Third: Don't try and be a Doctor with Google. Don't listen if you are offered any "it's probably nothing" best guesses of others (we weren't btw). If you, the parent, are in doubt, put your child in front of someone who has a degree in medicine. By the way, a Paediatrician studies Paediatrics for an additional 5 years after gaining their medical degree ie 10 years in total – and carries on learning throughout their career. The first Paediatrician we saw still didn't think that Baby's condition was presenting as meningitis, but it was the blood work and lumbar puncture that they ordered that confirmed bacterial meningitis.

Fourth: At 5 months old, our baby was fully up to date with her immunisations. Immunisations still don't make your child bullet proof against all forms of meningitis, so still be aware and take action if your parental instinct tells you that your child is out of sorts. The jabs and reaction afterwards are absolutely nothing compared to what our baby went through daily and in fact hourly during her first 48 hours in hospital. Make sure your child's jabs are up to date.

Finally: I don't mean to be alarmist about the many childhood ailments that will inevitably come and go in your child's life, but I do believe that parental instinct kicks in and you will know the difference between "a bit under the weather" and "seriously out of sorts". There are only 200 cases of pneumococcal meningitis per year in the UK.

I am not a doctor; I offer no medical advice other than take immediate action and seek professional medical advice if you have doubts.

PS. We have again seen first hand that our NHS Doctors, Nurses and staff are amazing people who serve us in the NHS as a long term vocation. They receive less financial reward than they deserve, and they give us their working lifetime. If they strike against the meddling actions of headline seeking politicians (who are in comparison mostly dramatically overpaid incompetent temps) we should support them.

[#DontWaitForARash](#)

From Spa Surgery doctors:

We are really grateful that this parent has shared his story in such a helpful and informative way. Our policy is to respond quickly to parents who are worried about their baby – the vast majority of cases are minor childhood illnesses but we never take any chances. Things do change quickly with children and young babies in particular so you will always be advised to keep a close eye on them and return if at all worried.

For more information on pneumococcal meningitis – go to Meningitis Research Foundation website

<http://www.meningitis.org/disease-info/types-causes/pneumococcal>

Know when to seek medical advice for your baby visit:

<http://www.nhs.uk/conditions/pregnancy-and-baby/pages/spotting-signs-serious-illness.aspx>

or

<http://www.whenshouldiworry.com>