

There are days we cursed, life too when it can be so cruel and unfair.

Zoe was sleeping deep this morning and I had a lot of trouble waking her up. If it first made me smile to ask to postpone our appointment, I stopped as our specialist told me that it could also be an additional sign of Zoe's deterioration. So I was going to take Zoe to the hospital, whether she wants it or not. And the fact that for the second time in a week she complains of pain in the thigh has reinforced me in the need to disturb her.

Sylvain warned me that he was working, but we had already lost too much time in France when we had not consulted. I thought the sooner was the best and today was "perfect".

I was well aware of Zoe's general fatigue condition and her hypersensitivity, even if it was progressive and the cold of winter and its viruses don't help. It's been 31 months since symptoms control (or not) our life, so I also know that there are days "without" and tomorrow "with". I am also aware that, in addition to the Love is the hope that carries us day by day. Anyway, too much thinking you mine then I avoid doing it to move on, except today wasn't really the routine visit that I certainly hoped in the bottom of me.

A first consultation together with Zoe, which I then took to the games room to be able to discuss with the doctors, who at no time have judged us. Hard words to hear, unbearable for a Mum, a Dad, or even anyone. Words that no one should ever hear.

Words certainly pronounce, unspeakable, for whom is concerned and I should have repeated in detail to Dad if I had not asked the doctors a written report of our surreal conversation, unfortunately very real.

"I examined Zoe today at her mom's request. I saw her with her mom, but Zoe's dad couldn't attend because he was at work. Dr. xxx was unfortunately not available today. Xxx was also present and xxx joined us for the first half of the consultation. I had the chance to see Zoe again the week before Christmas, before the family went to France on vacation, which allowed me to better understand his current situation.

Zoe had a good time in France with her family but unfortunately deteriorated in clinical terms. She's getting more and more motionless and can't walk anymore. She chooses to crawl on four legs if she is left to herself. She also complains of discomfort to the thighs. His voice is softer and less perceptible. She's still able to eat well, but it's slower. She's not choking. Sometimes his parents can hear his secretions accumulated at the bottom of his mouth. She pees and opens her entrails satisfactorily. She sleeps well at night. The deterioration has been gradual and nothing suggests an acute vascular event. On the exam, Zoe cooperates as usual. It obeys all instructions with precision and reliability, although its speed of treatment remains very slow. His voice is calm and indistinct. I had a lot of difficulty understanding her even if her mother could interpret her words. She has eye movements but is able to close her eyes and smile. She couldn't deflate the toys (she never knew). She raised her palate and could move her tongue to the left and right. She had secretions accumulated in her mouth. She ate a bun slowly during the consultation without difficulty. She showed up in a wheelchair and mom raised her on the bed to be examined. It's pretty

weak in the four members, with the legs worse than the arms and the right side worse than the left. The Mother supporting her under both arms, she could have taken a few steps.

I explained to mom that I agreed with her that Zoe's clinical condition had deteriorated since Christmas. I said that the gradual deterioration and the type of anomalies suggested a DIPG tumour progression and were not related to vascular stenosis. Mom accepted, then asked me what the next steps would be.

I said that Zoe, she and her father had fought exceptionally hard against this tumour, but I said it was my opinion and my recommendation that we now go to the control of palliative care / symptoms. I said we were asking questions about a possible third radiotherapy, but I didn't think Zoe would tolerate it very well and that the outcome was unclear. I thought there were risks and there was even a chance to reduce Zoe's quality of life rather than improve it. We then reviewed the possible scenarios that Zoe could meet as she became more involved. We talked about the continuing deterioration of mobility, the growing difficulty of speech / communication and the inability to swallow requiring a nasogastric tube. We talked about the pain and how we could deal with analgesia. We talked about the role of steroids in some periods of improvement, but due to the side effects of steroids, we couldn't use them at high dose for long periods. We developed the next plan.

MRI - I said that, under the circumstances, I did not think that it was absolutely necessary unless more radiotherapy was done. However, I would like to ask for one if the parents wanted

Radiotherapy - we will discuss Zoe with our paediatric radiotherapy colleagues at xxx at our Thursday xxx meeting on repeated radiotherapy will update Zoe's speech therapist who planned a visit next week and a physical therapy session.

Mum will talk to Dad and I proposed to see him face to face to discuss more in depth if he wishes - we will also send him a copy of that note.

I will contact one of my counterparts in Lyon, closest to the grand hospital of the family house in Chambéry, to discuss the possibility of palliative care on site.

I wrote an order for medicines].

Dr. xxx or I will contact Zoe's family again on Thursday after our multidisciplinary assessment meeting to keep her informed of what has been said.

Dr. xxx. 01/08/2019 @ 11 pm "

I would have tried to take on me, just for Zoe, that she couldn't see the distress on my face once the consultation was over. I listened, I managed to ask questions, I commented, I "defended" us against our non-choices since radiotherapy. The symptoms and signs of deterioration described, I read them on the internet or social networks, I know them, I saw them or even lived while we met so many little warriors. Warriors in Mexico, these same warriors we have too soon leaving, and their funeral we attended, all powerless. I was always listening, until, at some point, I couldn't talk so much it had become impossible, despite all my efforts. Tears, nothing but tears, and the need for silence, to isolate me, to get Zoe back and leave the hospital without seeing anyone or having to talk. The need

nevertheless to pass through the hospital pharmacy to remove our steroids that we will take eight days. 20 minutes waiting, and then no, 1 hour, and then 2 hours waiting, and this view from the hospital, with its smells, all this world, with all these horrors heard, that air from the hospital that had become unbearable. It's Sylvain who finally went to pick us up while it was already almost 2pm and Zoe hadn't eaten...

We are still waiting for the report of our visit to our vascular stenosis on Thursday, December 13 at Great Ormond Street hospital. Upon Receipt, we will send it to our Mexican doctors to have their views on the situation (the plane, the risks of an umpteenth general anaesthesia, those related to any intervention, our medicines, etc. ) and their position regarding possible treatment or not for Zoe.

A post certainly as long as this day, as challenging as that of 23 May 2016, day of diagnosis... if tonight, I stay collapsed, tomorrow, the fight continues.