

PRACTICE



WHAT YOUR PATIENT IS THINKING

Never say never about our child

In the latest of a monthly series in which patients and carers set the learning outcomes for readers, Alison Pearson asks healthcare staff to reconsider the concept of offering “false hope.” For more information about the series, contact Rosamund Snow, patient editor, rsnow@bmj.com

Alison Pearson

Until five years ago we were just an ordinary family, with a 3 year old son and a baby on the way. The baby became our daughter Isabel, who is a loving, happy, beautiful little girl much loved by her family and friends.

What makes us a little less ordinary now is that Isabel has Edward’s syndrome—she has an extra copy of chromosome 18. The way that medical professionals have responded to this fact has had a major impact on us, in both negative and positive ways. We are lucky; local paediatric doctors treat her as a valued child and focus on her symptoms rather than her syndrome. But we have had some unnecessarily difficult experiences with others, especially in the early days.

Three days after Isabel was born we were given her diagnosis, devastating enough to deal with but made even worse by the fact that it felt as if some of the doctors had stopped viewing her as a child worth helping any more. A particularly negative paediatric consultant told us categorically that Isabel would die within days, or at best weeks, and then gave us no support at all. One of the hardest things we had to deal with was when he told us quite bluntly that it was “not appropriate” to resuscitate Isabel should she need it; a conversation that still horrifies us.

After the initial gloomy prognosis, every subsequent illness at first made us wonder “is this it?” What made this so much harder for us was that in the first two years of Isabel’s life we were asked, at every hospital admission, whether she was for “full resuscitation.” Our answer then, as it is now, was always “and why wouldn’t she be?” Isabel has a fantastic quality of life as an important member of our family. Being asked the resuscitation question so often made us feel that doctors were questioning Isabel’s right to live, and to receive treatment, and

that maybe they didn’t feel she was quite as important as other children. We cannot fault the medical treatment that Isabel received, but we minded very much that we were routinely asked this question. Isabel has no ongoing pain, and nor does she have a progressive degenerative condition. So, is it asked because of her disability, and because she doesn’t have a “normal” quality of life? How do you assess this? In any case, many children who are perfectly able have a much worse quality of life for some reason or another.

Isabel has a joyful, shining personality, and she is very determined. We started a daily exercise programme last year and have noticed that this has helped hugely with her strength and development. The thing we focus on is that she is making progress, however slow, and we never say never in our house any more.

We know that Isabel is an exception, and that she is defying the statistics. We hope though that she may be an inspiration for others to accept what our current, wise paediatrician said: “statistics can tell you what may happen, but they can never tell you what one individual will do.” For us, where there is life there really is hope, and we would like more doctors to have the “never say never” view too.

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Read more about Isabel at: <http://ourmiracledaughter.wordpress.com/>

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The bottom line

- Be aware of your ability to create self fulfilling prophecies. The most dramatic of these is clearly the question of whether a child with an unknown future should have life saving surgery, but it is also easy to limit a child's chances by being pessimistic about what they will or won't be able to do in the future. Isabel is here enjoying life because we ignored the predictions and advice of many medical professionals
- For parents to be asked whether their child should be resuscitated or not is deeply emotive and a decision that has huge consequences. We strongly believe that, if the question does need to be asked, it should be discussed once and then recorded, with parents to agree under what (if any) circumstances they should be asked again. It is definitely not a "tick box" question to be asked routinely at every admission—that in itself trivialises the decision
- In the early days one doctor appeared to think that we were being too positive, so it seemed like he was trying to drum out all of our hope. But hope is what kept us going, kept us able to put one foot in front of another, helped us hold our family together. There is no such thing as "false hope"—hope is today's dream for tomorrow—and whether or not that dream comes true it can help today to be manageable
- Remember that parents need help too, not just babies and children. It is easy to overlook the physical and emotional needs of the parents when a baby is very ill. It helps us when healthcare workers treat Isabel as though she will recover, rather than assuming that she won't; when they acknowledge that she is our beautiful, happy, much loved daughter; and when they are noticeably pleased by her progress, or how well she is recovering from an illness, and let us know about good news as well as bad
- Using terms such as "dysmorphic features" and a "lethal condition," as well as talking about her "end of life pathway" in front of Isabel and her big brother is simply not respectful of us or our situation. We would urge you to think carefully about the words you choose to describe children to their parents, and to be mindful that even quite young siblings may overhear your conversations if they are present, even if they seem not to be listening

Resources for your patients who are looking for peer support

Trisomy Mommies. Facebook. <https://www.facebook.com/groups/T18Mommies/>
International Trisomy 13/18 Alliance. www.internationaltrisomyalliance.com