



Does my daughter have a quality of life? I don't know. Do I love her? With all my heart. When she dies, will it be a relief? Without question

By Tussie Myerson

My eldest daughter, Emmy, was epileptic in the womb. This means that the abnormal foetal movements during the last two months of my pregnancy were actually epileptic seizures. She had her first seizure outside the womb at three months, followed by many months in hospital, before being discharged into my completely untrained hands.

Emmy, 18, has what the professionals call PMLD – profound and multiple learning difficulties. She is quadriplegic, with cerebral palsy and intractable epilepsy. Basically that means that she is buggered. She cannot walk, talk, toilet herself, feed

herself, etc. She can communicate in a fashion, by laughing, crying and smiling, but you cannot be sure that it is controlled. When she was 10 months old (1992) we were told by the wise and the wonderful at Great Ormond Street that she would die very soon. If she didn't die very soon she would die a little bit later. If she didn't die then she would probably be a vegetable for the rest of her "short" life. There was no counselling or support. We saw a geneticist who told us not to have any more children, and that was it. There was the usual gaggle of meetings with social services, who offered us residential care or possibly a bit of respite in the community, but they weren't sure. Our GP was very kind, but she had never had a case like this before.

For the next 18 months I had to deal with the

hugely complex array of appointments, whilst having this dreadful thought in the back of my head that my daughter was going to die.

She didn't. I stopped believing the doctors. I started believing in my daughter.

And yet no one believed in me. There was no joined-up thinking. No early intervention, no support structure. No recognition of what that day at Great Ormond Street had done to us as a couple, or our little family.

When you give birth to a child whose life is going to be bombarded with medical complexity, you begin a journey that is impossible to be prepared for. For the first 10 years we simply existed. Every few months she would have a bout of pneumonia and we would prepare for her possible departure. It was a staggeringly

difficult time. When she was four we found Helen House Hospice in Oxford, and thanks to them many of these interruptions were made more manageable. We came to understand what "life-limiting" meant. And how to come to terms with the fact that our gorgeous child was not going to live into adulthood.

We still had little or no support from our local authority. I think we got a respite weekend a month, for a child who could have up to 40 fits a day and was heavily medicated. Plus I had two more babies. We had a social worker, but to be honest I can't remember her. I think I saw her twice a year to review the care package.

We also received little or no support from our families. My parents did a fair amount, when she was well. David's family live in the US,

which isn't really convenient for babysitting.

Coming to terms with your child's passing is a journey that is very difficult to explain. It doesn't really happen overnight... well it didn't for us. It wasn't like there was one day when it dawned on us. But repeated events. The pneumonia and recovery, maybe it started to take a little longer. I couldn't say. But even at eight or nine I think I had still fairly idealistic. I knew she could go, but I hadn't really got my head round her handicaps. We had, after all, had several near misses already. But she was still such a baby in my eyes. And the steel cage I had built around myself to protect me from the so-called "professionals" worked very well. Unfortunately what it also did was block out my husband for a lot of the time.

Her brother and sister were also still very small. As they began to gain some independence reality began to strike. She was still here. I was still caring. All the time, three hospital appointments a week, often more.

But at no point was there one person who stuck with us, to catch me as I started to fall. Briefly there was one social worker who went above and beyond; but she got disillusioned and left the profession.

Because of the nature of my daughter's diagnosis we, my husband and I, decided early in her life that we wished her care to be palliative. To most people this would mean end-of-life hospice care. But for us it means whole life care. Which means that her life is about quality now, rather than using medical intervention to keep it going. Therefore we do not wish her to be tube-fed, to be resuscitated, have intravenous medication other than pain relief, or any other intervention.

Her quality of life is about being able to make the very few decisions she can make herself. This includes eating, which is under her control. And breathing.

She and I have "agreed" many times over the years that it is her call. She decides if she is going to wake up, not me. So far, she has chosen to wake up.

When we first asked for no intervention I don't think we fully understood what we were saying. It was more a reaction to what everyone was doing and taking into account the fact that they kept telling us she was going to die. So if she was then let her. But now I do understand. She should never have survived. For whatever reason, she did. That does not make it right to keep that life going "just because you can".

What a family like ours goes through is grieving for a very long time with the end never actually happening, and also caring. So two of the most stressful jobs wrapped up in one package. It appears to be taboo to admit how hard it is. As a society we don't seem to want to admit to the hurt of watching our children live half-lives, quarter lives even. Does Emmy have a quality of life? I don't know. Do I love her? Absolutely. Will I miss her? With all my heart. When she dies, will it be a relief? Without question.

Gradually you recognise that extending this life, it isn't your call. You are simply a manager of a body. It is down to her if she wants to keep going. My job is to make sure she is comfortable. That she has a reason to smile when she can. That she is loved by her family, and at the end of the day her family have the energy and capacity to love her.

Society now appears to be about extending life. Ticking medical boxes and covering arses that enable life to be prolonged without necessarily asking the terribly important question. Who are we doing this for? Because it is not for me, or my family. We have been through quite enough. And I cannot imagine it is for my daughter. What she has had to go through does not bear thinking about.

And why is it still taboo to talk about this issue? Why, with an ageing population, and more babies surviving premature birth and birth trauma, is it still considered politically incorrect to tackle the really important and, let's face it, unavoidable

issue, of who are we maintaining life for? I can only speak from the experience of my daughter. I do not know what it is like for anyone else. I would never claim to know. But I do feel that it shouldn't be wrong to say what you really feel.

Why is there nowhere in this country that provides long-term palliative care for young people whose lives are not going to be improved by medical intervention? They are just going to be extended. Extension does not mean made better; it just means longer.

The decisions that have to be made are complex. But decisions have to be made, and this is clearly where a huge problem exists, because no one wants to make them. You are held hostage by a social welfare service that is not structured to provide care but to avoid spending money. And the sad reality is that children and young people with complex health needs cost money. Families can't even

be paid properly for the care that they provide. My daughter is now 18. Were she not profoundly disabled she would be at college or something. Were she out of work she could claim housing benefit. But as a profoundly disabled 18-year-old living in an annexe of her parents' house she is not allowed housing benefit because her landlord is her father and God forbid she may be abusing the system. No one will support her accommodation needs. Why? Well, that is the question they must answer, because we certainly didn't realise that in her being at home we would be paying for her accommodation and that of her two carers as well. Maybe I am being petty here, but when my daughter was discharged from Hammersmith hospital in 1992 no one told me that I would still be fighting 17 years later. No one told me that my fight would get as ugly as it has done. No one told me that I would be judged by people who had/have never met her and have refused

to meet her. Or who would twist the situation to avoid facing up to the horrific reality. We, her parents, have had to make decisions that no one else will face. Quality versus quantity. Palliative versus intervention. It is just adding insult to injury that my daughter becomes a box-ticking exercise rather than one of decision-making.

I am not alone in my outspokenness on these issues. But maybe right now I am just that little bit angrier that it is discretionary, not legal, whether Worcestershire County Council meets her housing needs. Discretion should not come into it.

If we are going to maintain life then we have to treat those who are managing those lives with respect. That includes the carers, the families and the individuals themselves.

We don't do that. Our local authority has spent more avoiding their responsibilities than meeting them. And that is wrong.

Would your joints care for 50% extra free?

50% EXTRA
FREE



- Helps protect supple and flexible joints.
- JointCare Original contains Glucosamine® – a unique combination of glucosamine and omega-3.
- Clinically tested formulation.

SEVEN
SEAS

Jointcare

3 for 2 Available at most *Boots*
Cheapest free

Visit www.jointcare.com for joint health help and advice



Do you recognise this description of family life? What should be done to make life easier for profoundly disabled children and those who care for them? Tell us about your experiences.

Write to:
yourstory@independent.co.uk