

Living with the Consequences

by Nigel Thomas, older brother of two affected children

(presented at the Thoughtful House UK Conference, March, 2006)

I should start by saying that I've always been a great admirer of science, even if not a great participator of it. I remain convinced that I discovered a new substance when I was at school by recklessly mixing the bottles of chemicals together when I was supposed to be testing them with litmus paper. My container of steaming bubbly green liquid was greeted with the kind of horrified contempt I've come to understand is perfectly natural in scientific and medical circles when you discover something that other people either don't like or don't understand. I too had my funding "pulled" in detention.

Allow me to introduce myself--my name is Nigel. My older brother Ian is twenty-eight and my two little brothers, Michael and Terry, are thirteen and twelve. Ian and I didn't have the MMR, and we've grown up healthy without any problems. My two little brothers both had the MMR and have complex medical problems including autistic enterocolitis. In this speech I hope to tell you a little about a brother's perspective of family life with two seriously damaged children, and how it's affected us. How these families are not the paranoid, crackpot blamers that newspapers have on occasion represented us as. And how justice, and more importantly help, for seriously ill children is not an unreasonable request.

I think the first time I realized something was not exactly how it should be was when Michael stopped breathing. It was a few days after he had had the MMR vaccination--but that's probably a coincidence. Isn't that the age when babies tend to stop breathing anyway? Have I done any actual tests? No, that's just the general trend--isn't it?

Things were never really quite the same after that--but being quite young at the time, it was hard for me to see something was wrong. I didn't really have a basis for comparison. I just thought that my little brothers were exceptionally naughty and that that was just the way little brothers behaved. I knew they were ill too of course,

but like the government, I didn't really look into it much--I thought it was just a phase they were going through. A start-of-life crisis.

It seemed the doctors were of much the same opinion--when asking my youngest brother Terry about this, he said that one doctor had told him "I do believe you're in pain, but it's something you'll grow out of." Unfortunately, most of the children like Terry who are no longer in pain are the ones who have passed away.

It all seemed to happen very quickly--more so for me I think, as I was at school, so the differences in my brothers--and indeed, my whole family--were more noticeable. My perfectly normal and healthy brothers were starting to become neither. I remember wondering why Terry was so yellow--why Michael had a horrible rash--I wondered if I could catch it. So what were the symptoms within the whole family at this stage? Well, from my perspective: crying irritated children, crying irritated mother, irritated father, and nonchalant older brother (sometimes irritated--definitely more withdrawn). Stop me if I'm getting too technical. It's no wonder that I started to feel annoyed.

Seemingly overnight, I lost my mother, and she lost two children. Physically they were still there, but nothing was ever the same. My mother took on the look I've since seen in countless mothers I've met with children similar to Michael and Terry, which I've dubbed the "MMR Mothers look," and it's a look that can be summed up in one word. *Exhaustion*.

It's a look that shows the strain of having two children who are falling ill, and nothing's helping them and no one's listening to you. It's the look of wondering what new symptoms your child's going to develop the next day, the look of not knowing if they're going to stop breathing in the night, the look of helplessness. I can't help but laugh when I read articles about "over-emotional mothers" and that "you can't take their word for it--they're just too emotionally involved." Show me the mother who isn't emotionally involved with her child, and then show me anyone who really knows more about a child than the child's mother.

But it's not just Mum and Dad being silly. I've witnessed my brothers grow up and have seen the changes in them with my own eyes. I've seen doctors tell my parents that there's nothing wrong with my brothers. I've seen my parents struggle for even basic recognition that my brothers had problems. Unfortunately, it was all too often the case that we had to wait until Michael or Terry was rushed into hospital before someone would say, "This child is unwell."

On the evening that Michael had the MMR he started screaming—high-pitched screaming. My mother phoned the nurse who had given him the injection and asked if it was related to the vaccine. Her words clearly demonstrated the wisdom of her years, and were rich in medical detail as she proclaimed, “Pull yourself together Mrs. Thomas, some babies do that.” There was no examination, no tests. Nothing. I don’t think Michael even got an “I’ve been good and had my MMR” sticker, or rather “I’ve been good and had my MMR because the government won’t let me have anything else.” But we’ll come to that point later.

So, what’s the worst thing about being the brother of two children with autism and bowel disease? Firstly, for quite a long time, I didn’t really like my little brothers at all. No, I’ll go further than that—I think I hated them. I mean, who were these two little BRATS to come into my life and take my mother away from me?! That’s really what it felt like. Suddenly all my mother’s attention was focused on these little crying creatures who touched my things, made stupid noises, and wrecked things. It was *their* fault that my mother came back crying from the doctor because they wouldn’t listen to her and wouldn’t help her. It was *their* fault that my parents were so sad, and it was *their* fault when they argued. In fact, if anything bad happened, I usually attributed it in some indirect way to Michael and Terry.

Not only that, but I was ashamed of them, and embarrassed to go out in public with them. I just couldn’t understand why they wouldn’t do as they were told. Don’t touch that. DO NOT TOUCH THAT. You’re not allowed to. No. You’ll be in trouble if you touch that. Ok? Don’t touch. NO! And as the last words were leaving my lips, I’d see this little hand moving forward to touch. Of course I’d get cross, and then my mother would get cross with me. That was the worst thing—I was the good guy! This was a little villain, and yet I was the one to be told off. “Leave him alone, it’s not his fault!” Yes it is! Look, this little hand is attached to his arm! It’s connected to him! I told him not to, and he touched! “Leave him alone, you should know better!” And so then I’d resent my mother as well as my brother, and probably make life even harder for my poor mum who had to deal with the whole situation in the first place. Michael and Terry used to have T-shirts that said, “I’m not naughty, I’m autistic.” I hated those. At the time, it felt like it was an excuse. I knew they had autism and bowel disease, but it just didn’t seem enough. I just couldn’t accept that it

affected their behaviour, especially as they deteriorated. They were becoming increasingly behaviourally affected, and so I was comparing them to the time when they weren't so bad, and weren't so ill. In my eyes, I didn't see them getting more ill and more autistic, I just saw them getting more naughty.

It would have helped me to see tubes coming out of their heads, and for them to be attached to machines, and then--fair enough, you're not naughty--or at least if you are I can visibly see why! It took me a long time to realize that if their own brother couldn't understand their problems, what chance would they stand with anyone else in the world?

This has so often been the problem--if you spend five minutes--well, two or three from my last visit--with Michael and Terry on a good day, you might think nothing was wrong with them if you weren't really looking. They have the same shape as any other child, same number of arms and legs. As I gradually started to understand their condition and how it made them behave like they did, I started to see how terrible I had been myself, and how awful it was to see how other people reacted to them and to my family in public.

I asked Michael, "What's the worst thing about your condition?"

He said, "Being different from everyone else. Knowing that you're different." What made me as a brother realize that he was different? I think it was seeing my friends' brothers and sisters of a similar age, and how they behaved. I was so cocooned in my knowledge of how children of that age were supposed to act that the way my brothers behaved just seemed normal. It was a shock to see how differently other children behaved. They were so tiny, and yet it was almost as if they were mini adults! Why weren't they making silly noises?! Why weren't they hitting each other?! What was wrong with them? They were able to eat without being in pain! They only took five minutes to go to the bathroom! It was a revelation. And a sad one, because I wondered what Michael and Terry would have been like if they didn't have autism. What kind of brothers had I lost? What kind of people would they have grown up to be? I'll never know now. Who was to blame for this? What caused their problems?

I think that what finally made me accept my brothers' problems was the realization that it wasn't their fault. They wouldn't be able to act differently if I

shouted at them, I'd only make their lives worse when they were already both almost constantly in pain. They themselves had already, to a degree, accepted it. I thought they whined about how ill they were too much, until one day I talked to them about it. They said they were frequently in pain, and sometimes it just never went away.

Michael said he knew he acted silly sometimes--shouting and dancing around, but that he couldn't help it. I remember getting annoyed with them for leaning their bodies across the armrest of the sofa for hours at a time and wagging their feet, until they told me it made their tummies feel better and they liked it. I learned all this by talking to them--not using baby talk or patronizing questions. Autistic children are not idiots. Just by asking direct questions you learn things they'd never have told you otherwise, because it doesn't occur to them to do so. From my experience seeing doctors examine my brothers, this is one of the most underrated diagnostic tools--talking to the child. It really adds to your understanding of their condition--it did to mine.

Lots of reasons have been given for why Michael and Terry have the painful and debilitating conditions they have. All of the below are real quotes from doctors:

- Food – their diet must be funny.
- The parents – what are they doing to them to make them autistic?
- A phase – they're just growing pains, there's nothing wrong.
- Their medication – they must be on the wrong medication. (OK, but that doesn't really explain why they're on medication in the first place.)
- It's normal and natural. (A lot of children grow horribly ill naturally at this age. Blame Mother Nature.)
- There's nothing wrong with them! They're just seeking attention. (How many children do you know who seek attention with bowel problems? Rashes? Fever?)
- They've got a low immune system--they'll grow out of it.
- This is not our remit.
- The pain they're in is just their autism.
- Your expectations are too high.
- Pull yourself together – some children are like that.
- I'm not 100% sure what's wrong with them, but I'm going to find out.

(I'll leave you to guess which doctor said the last one.)

Now may be a good time to say something directly about the MMR, so I'm going to divert away for a moment from my family tale and ask that you indulge me for a moment with some of my own opinions and observations from a brother's perspective.

You may say that I seem too certain that it was the vaccination that was the catalyst for all of my brothers' suffering. Well, I am certain, but if the government want to change my mind I would welcome them to do so. All they'd have to do is something they've refused to do to a SINGLE child who claims to have been damaged by the MMR. Examine my brothers. If it's not the MMR, fine--prove it to me. If it's a new medical condition that wasn't caused by the MMR, OK! If you're so certain, why don't you spend some money on finding out what did cause them to be ill. I don't think we're being too unreasonable by asking this--it's not like we want the moon on a stick. How many deaths are needed before the children's illnesses are taken seriously?

Journalists love to call mothers and fathers who dare suggest that the MMR may have caused their children to fall ill "anti-vaccine" parents. The misrepresentation of families like mine just adds another weight to the pressure that we're already facing. I think certain people would love to think that such families are unstable, emotional, almost militant campaigners who want to bring down the national health program and stop every child from getting any vaccination ever. They need to try to undermine the families in order to undermine the importance of the questions they ask. From my perspective these would be: why are my brothers ill? What caused it? Why won't the government examine my brothers? And what can be done so that my brothers are no longer in constant pain?

I'm sure many of you are familiar with the current drive in the NHS to give patients more choice. For example, you've got Choose and Book, where you'll be able to book appointments online to see your doctor where and when you want. You'll also soon be able to pick and choose which hospital you want to go to. The NHS choice website suggests, amongst other things, that you need to: "Consider your needs and compare each hospital using the information you have, bearing in mind what is most important to you."

While working for the NHS, I went to a presentation for healthcare professionals and working parents by Robert Duff of the Department of Health. When he was asked why parents weren't given the choice of single vaccines, Mr. Duff said that: "You can't always have choice. You don't have a choice of whether to wear a seatbelt or not." True, but there isn't a group of drivers going round saying they won't wear a particular kind of seatbelt because they're worried it isn't completely safe. They would allow people the choice of another type of seatbelt if that were the case--after all, lives are at stake.

So much talk about choice, and how important it is! I think it's a great policy--patient choice is a good thing. I just think they should extend it to vaccines too. The DOH say that you can't choose to have single vaccines because "they can't licence something which isn't as good for the child as the MMR." Yet you can choose a hospital which may not be as good for you as another. You're allowed to "bear in mind what is most important to you," but not when vaccinating your children. It reminds me of the kind of choice Henry Ford offered when first mass-producing cars, when he said, "You can have any colour you like, as long as it's black."

So, choice is important. But measles is also a terrible virus, and I can see why it's important for children to be protected against it. The government and the media frequently say that parents are irresponsible if they don't get their children vaccinated, as they might pass measles on to other children. I still think this is a reasonable position. Herd immunity makes sense. BUT if measles is that important a worry, surely it's only common sense to provide a single vaccine choice if parents are worried about the MMR--whether they're right or wrong is irrelevant! If they offered the single vaccine, more children would undoubtedly be covered against measles, which surely is the aim of the Department of Health. It would surely help achieve the herd immunity that they claim to be their holy grail. But they don't. Instead they accuse clinics that offer single vaccines of profiteering, because they have the cheek to offer parents a *choice* for their children. A choice of what to inject into their babies. A choice of how to live their lives. Michael and Terry can't choose how they want to live--that choice was taken away from them.

The final thing I'm going to say regarding this is that I find it distressing that when groups of parents decide to work together like in JABS they're called "anti-vaccine," and a "pressure group." I find this incredible in light of the fact that the

only pressure I've seen them apply is on parents to be properly informed in the debate. Though I've never had anything to do with JABS, I've been in the room for countless phone calls, and I always remember noticing how my mother used to say "we can't tell you what you should do, just make sure you get all the information you can before you make the decision." I doubt I would have been so impartial if I were the one on the phone. In fact, I'd probably just pass the phone over to Michael, and let him tell them! GP's surgeries on the other hand have a significant financial incentive to ensure that their patients are all vaccinated--if they don't give the MMR, they get less money. I'll leave you to decide which one is the real pressure group.

I'm sure I don't need to tell anyone here that Dr. Wakefield has come under attack for what he's done. I've always thought it odd how most of the abuse comes not in the form of reasoned scientific attack, but personal abuse and jibes. People say that he offers children like my little brothers false hope. The only doctor to actually examine my two little brothers is accused of giving them false hope! It's like driving round trying to get your car fixed. The only mechanic to actually look under the bonnet is accused by other mechanics of giving the driver false hope that it can be fixed, when they haven't looked themselves--but they've tested other cars of the same colour, and they're fine, so what's all the fuss about?!

I don't want to go on too long about this, but I feel it's important that it's understood that the families are under no false delusions of a mystical cure. We hope that something to help alleviate the symptoms can be found, but it's common sense that the children involved need to be looked at first. How can you find a cure until you've examined the patient? Not a study of similar patients in similar situations, but the actual PERSON who is unwell. Not a difficult or groundbreaking concept. I asked my brother Terry a final question, "What do you think of Dr. Wakefield?" His reply didn't contain lashings of praise, or anything to do with him being the magical doctor who will cure him of his constant pain. He simply said, and these are his direct words, "I like him because he was the only doctor who didn't turn us away." That's higher praise than anything I could lavish upon him. Thank you Dr. Wakefield.

So how does my family draw strength to make it day to day? Knowing that we're not alone helps. I used to get so sick of my mum being on the phone all the time--often to the detriment of my dinner--until I started to realize that she was talking

to other mothers and families who'd had the same experiences as we had. It wasn't just us--there was a pattern. And so families can draw strength from each other by sharing information, and telling the stories of how they've coped.

My speech is titled "Living with the Consequences," and obviously in my family Michael and Terry have the biggest consequences, but at least they are "living" with them. It's always sad and quite disconcerting when my mother tells me another child with a similar condition to my brothers has died.

What are the other consequences for a family? It's an old cliché, but it really does turn the family upside down, and frequently, inside out. I know that not all families make it--why? The strain. Take all the normal trials and tribulations of a couple. Add children. Garnish with severe disabilities appearing suddenly out of nowhere in those normal children. Bake for 40 minutes without anyone really knowing what's wrong with them, and add the stress of no one bothering to look at the children to actually find out. Voila! The MMR family.

What's the best thing about being the brother of two children with autism and bowel disease? I've thought about this a great deal, and have tried to make a list about what's good about being the brother of two autistic children. My list is empty. I can say quite categorically that there's NOTHING good about it. That's not to say there aren't a lot of great things about being a brother, but about being the brother of vaccine-damaged children--absolutely nothing springs to mind. Unfortunately, you simply can't separate the autism from the brother. Some might say how wonderful it must be to see how brave Michael and Terry are--and they are, but it's not wonderful to see. Because seeing them being brave is seeing them biting their lip because they're trying not to cry out in pain. It's seeing them in hospital, in agony, and knowing that the doctors aren't going to be able to do anything. I'm proud when I see how brave they are, but I hate it. Children shouldn't have to be like that all their lives--they deserve better.

I think the only time I've found any benefit in being an autistic child's brother was when I used to use it as an excuse. If I got into a horrible mood with someone, or if I didn't want to go out to a party I'd say, "My little brother is in hospital, I can't go," or "The reason I said what I did was because my brother is ill." Sympathy please, thank you. When it wasn't actually the whole real reason. Well, I'm sure that my mood was frequently and seriously affected by what was going on, as it was for

all my family, but when I was younger I think I might have used it more than I needed to. I think in a way, it made it easier for me to cope, as it seemed the only thing my brothers could do for me that wasn't negative. It seems very selfish to me now, but it was a learning curve I had to experience. I'm glad to say that now I've realized that it should be the other way round, and that *I* should be the one doing something for my brothers. There may be nothing great about being the brother of two little boys who are autistic and in constant pain, but I wouldn't trade Michael or Terry for anyone else in the world.

However much guilt I feel about my lack of understanding of my brothers' condition when I was younger, I am certain that the people who will shoulder the most guilt in any family whose lives have been deeply affected by vaccine damage are the mother and father. When I first spoke to my own mother about this, I was shocked to hear that she felt responsible for what had happened. Having thought about this, I can see *why* she might feel like this, as mothers are naturally the ones who control every aspect of their child's lives for years after their birth. But how can a mother blame herself for following the advice of people in the medical profession who are supposed to know what they're doing?

That's not the end of the guilt parents feel in families such as mine--no one came to see me in any of the plays I took part in over my three years at university. Or any of the performances with my band. No one in my family came to my graduation. I've been in London working and performing since 2003. My Mum and Dad have never come to see me. And you know what? I wouldn't have it any other way. Because I know that if it was the other way round and I was the seriously ill child, my family would do the same and stay looking after me as well, and that's just how it should be. And every time I step on stage to perform it's more special and I do it for my family and for my brothers, because I know that they may never have the chance to do everything that I've been lucky enough to do--they had that taken away from them. So I'd like to take this opportunity to say to mothers and fathers who have autistic children, and especially my own mother, that you shouldn't feel guilty--not for anything. That you're not alone in your fight to find out what caused your children to be so ill, that there are brothers and sisters out there who have seen and heard everything, and can help--at the very least by telling our story. Outside of that there

are grandparents, aunts, cousins, nephews--so many people who have their story to tell too. It's not just a small group of parents who have seen what has happened to these children, as the government would have us all believe. It was Edmund Burke who said, "All that is necessary for evil to succeed is that good men do nothing." We're each a piece of the jigsaw, and we can all do something to help those who need it, who can't express themselves.

It's hard for Michael and Terry to express themselves--as their older brother, I have had that privilege. Thank you.