

## **Alexander The Greatest**

"Go and enjoy yourselves. He'll be fine."

With those words the nurse gently guided my husband and I out the front door.

It was the first time in years that we had been able to leave the house together with a night of relaxation ahead.

Since our son Alexander was born in December, 2004 with multiple health problems, our lives had become an endless round of hospitals, sleepless nights and just about hanging in there.

Now for the first time there was some relief and support in the form of a nurse from the Jack and Jill Foundation.

As we drove off my mind wandered back to the day two years before when a doctor had finally diagnosed our son's condition.

"Your son has a profound mental and physical disability. He will never speak, he has a 90% chance of developing epilepsy, he might not walk before he is 8 years old and he will always wear nappies. He could have hirschprung disease (a serious intestine condition), heart, kidney and other problems...."

We were numb with shock. I could feel the sobs heaving into my throat. When we had arrived at the hospital we had expected to have yet more blood tests taken, more prodding and poking as yet another doctor pondered what might be causing our 15 month old baby's profoundly delayed development. Most youngsters Alexander's age were running about, while Alex could barely sit without help.

We had known Alex had a problem, but we had hoped it would not be as devastating.

"How long will he live?" I asked.

"With good care he could live until he is 65 or you could find him dead in his bed tomorrow."

The doctor's prognosis was overwhelming. Alexander had been born with an extremely rare non-hereditary genetic condition called Mowat Wilson Syndrome.

During the past 12 months we had been referred to 13 different consultants...and now finally we had an answer. But, it was not the answer we had hoped for or expected.

That afternoon we broke the news to our two older children. They were fantastic.

“He was our brother this morning and he’s still our brother this afternoon. This changes nothing. We love him!”

It’s easy to love Alexander. He is cute, with a killer giggle and a smile for everyone. He might not speak, but he communicates more deeply than most people who never close their mouths.

Alex is nearly five years old now and there have been many ups and downs. Having Alex has redefined everything. Now a good day is any day we are all at home and not hovering beside Alex in a hospital bed.

At first you grieve for what will never be – Alexander will never go to university, get married, or have children. Then you worry about who will look after him when you die, for he will always need full time care.

There is a rhythm to most people’s lives. They grow up, marry, have children and their children leave home. Alexander is ‘our forever baby’.

Life is good and filled with love, but life is also grueling and relentless. We are running a marathon in caring for our precious little boy.

Our calendar is filled with doctors’ appointments and hospital visits. I now truly value the good health enjoyed by our older children.

Alexander still sleeps in a cot at the end of our bed. At first we kept him with us, sleeping with one eye open, because we feared the onset of epileptic fits that are so dangerous, then he became ill and stopped eating and was fed through a tube in his nose. If the tube became dislodged his formula could have pumped into his lungs and killed him. He is still fed through a pump, but this year a special feeding tube called a PEG was inserted into his tummy.

Our house now resembles a hospital storeroom with syringes, medicines and other medical supplies. But, for all the clutter we are really grateful for it tells us that Alex is with us. In an earlier century he would have been dead.

At one point about two years ago, both my husband Declan and I were close to collapse. We were simply exhausted. Some weeks we would find ourselves in the Accident and Emergency Department of the Hospital several times a week. Often Alexander would be admitted for days or weeks at a time.

These hospital periods together with caring for our other two children and running a family business was almost more than we could manage.

Support wise we had an amazing, loving child minder who is also Alexander's godmother. Mary had more than stepped up to the mark. She had learned how to syringe with the best of us. But, with no family close by and friends who were supportive, but nervous of helping out with so sick a child, we desperately needed more back up.

We knew that if we didn't get more sleep and rest soon, we were going to crack up. Both my husband and I had been in a couple of minor car accidents that we knew could have been avoided if we'd not been so exhausted.

A few friends suggested we try to find a nurse to give some relief. Some people might miss having dinner out, movies, a weekend away at a swish hotel, but we just craved sleep like a junkie craves drugs.

We made a few enquiries, asked nurses at the hospital if they knew of anyone who did private work. They suggested we contact some agencies, but we found the cost of hiring a nurse regularly was prohibitive.

Another friend suggested we contact the Jack and Jill Foundation that they might be able to help. I spoke with one of the nurse organizers, Sinead and completely broke down when she said that with Alex's condition we would be eligible for regular support from a qualified nurse coming into our home.

Jack and Jill then worked hard at finding the 'right' nurse for us. One who would fit in with the family and that Alexander would 'take to'.

This support, which is completely free, has literally been a lifesaver. I don't think either my husband or I fully realized how close to complete exhaustion we were before the Jack and Jill nurse became a regular visitor to our home.

We can now enjoy some "normal family" outings with our older children, that we can't do with Alex. When we do go out sans Alex, we miss not having him with us, but we also appreciate doing things that regular families do.

One of the biggest dangers when you have a child with a disability is to focus all of your attention on them to the detriment of other children. It's something we are really aware of and so our house is often a jumble of children of all ages on sleepovers.

Alex still takes up a huge amount of our energy and each new year brings new challenges. We've learned Alex has two other life threatening conditions, apart from his genetic condition. He has

very severe allergies that have led to an anaphylactic episode and earlier this year doctors discovered he has a metabolic condition that if not treated swiftly can cause death.

So life is challenging, but also more interesting and rewarding.

A while back Alex's godmother had tears in her eyes as she told me how she is sometimes overcome with emotion when she looks at him because he has brought so much joy into our lives. And it's true.

Alexander is a pure spirit. He gives love totally, with exuberance and abandon. He is honest and open. He laughs when happy and screams when frustrated. He wears no masks. He is totally loving.

He has each of us firmly wrapped around his little finger. Nothing is too much trouble if it's for "our baby"! He is the antidote for bad humour and a day of knocks.

If ever anyone was to offer to replace Alex with a 'healthy, normal' child, I know we'd all say, "No thanks, we'll keep our Alexander!"

But, enjoying the richness that Alexander has brought into our lives is that much easier with the backup of our Jack and Jill nurse who gives us the Time Out to recharge the batteries for taking care of our precious boy!

The Jack and Jill Foundation relies on donations and from revenue generating schemes. Recently the charity received a huge boost when it gained support from the Alltech-Muhammad Ali Global Education and Charitable Fund.

This Alltech-Muhammad Ali Fund has launched a scheme in the 110 countries that Alltech, a biotechnology company operate in to raise funds by asking people to donate their old mobile phones.

These old phones will be reconditioned and sold on in the developing world where there is a huge market for such products. A real win-win situation - support for families with sick children and recycling of old phones.

To help please send your old phones to: XXXXXXXXXXXXXXXXXXXX

Do this, and more families like us will hear a Jack and Jill nurse saying,

"Take a break. Go and enjoy yourselves. He'll be fine."