

My name is Anne and I am married to Liam. We live in the countryside on a farm. We have one little boy Seán who is six years old. He is a beautiful, healthy and happy little boy. He loves nothing better than feeding calves with his Granddad every morning or running around in the fields and some days you can even hear him hammering away outside building his latest invention.

Our story with Temple Street Hospital began when Seán was nine months old. Without any warning, Seán became critically ill just shortly before his first Christmas. He was rushed to Temple Street Hospital and over the next few days our world crumbled before us. Seán had been diagnosed with a life-threatening metabolic disorder known as GA1. We were very unsure of what the future held for Seán and for us as a family. We were told that Seán would require a very strict and specific dietary regime and when he was unwell he would need a lot of extra care and perhaps even very frequent hospital admissions. We couldn't believe what we were being told. How were we ever going to cope? Liam was a full time farmer. A week previously I had suffered a miscarriage, so as you can image we were completely grief stricken but we had to push that all to one side to learn and understand this new world that we had entered; medications, protein substitutes, exchanges, unwell plans etc. etc. Life as we know it had changed completely.

We were given every assistance possible from Temple Street Hospital, from the nurses to the doctors and the whole metabolic team that were to become part of our family.

Seán first arrived home after his diagnosis, the day before Christmas Eve 2009. We were distraught and frightened. How would we care for him without the hospital? However, that very day we received four phone calls from Temple Street checking in with us and perhaps not the first day or the next day but soon we began to discover that we weren't alone. We discovered that we could always look for help and that it was only a phone call away.

From that first time home we have had several hospital admissions, too many to mention here. There have been tears and heartbreak but gradually as the months passed, the times between the admissions got longer and our quality of life began to improve. We had powerful help from our families and friends, as well as the medical staff which pulled us through the worst times.

Now, today is August 15th, we are just home from a fantastic holiday in Kellys' Hotel in Rosslare. We brought all of Seán's food, meds and drinks etc. Apart from his diet and meds, he was no different from any other six-year old boy.

He is about to start Senior Infants at the end of August and he is getting on great in school. He takes his own packed lunch to school and his teacher discretely makes sure it is all eaten.

To any new parents of children who have been diagnosed with this condition or similar; yes, it is a difficult road at times and you have to plan ahead all of the time, but life does go on. Life will be great again and you will smile and you will again. Believe me.

Anne, August 2015