

My Grumpy Thumb

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*The journey of a father coming to terms with the
death of his son*

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This book is dedicated to all those families who are forced upon the journey of caring for their sick child. I say 'forced' because no one would take this journey voluntarily and it is truly a journey no parent would wish

upon any other human being. However, for those of you setting foot on this path, some of the steps you will take will be paved with gold, memories which will keep you warm in the cold days ahead. Real life is not about 'happy endings' but more about seeing the joy you have within your grasp today. Wishing for better days tomorrow simply means you risk missing the opportunities of today.

ACKNOWLEDGEMENTS

My heartfelt thanks must go to my daughters Jeni and Sair who continue to give me the love and support only a father can understand. They also continue to provide me with the encouragement to get this work into print! I also send my love and sincere thanks to Gareth's mother Glen, without whom I would not have had the opportunity to experience and survive such tragic events in my life. I hereby acknowledge the copyright of Glen's words and thank her for agreeing to the publication of them in this special book dedicated to Gareth.

My final thanks must of course posthumously go to my son, Gareth. Throughout his illness he never failed to express his love for life and perhaps more poignantly his love for his sisters and parents. He certainly lived for 'the day' and in the process had such a positive impact on so many people in his short life. Despite his very young age, he taught me so much about living my life. I remain so proud of the fact that he was 'my son'.

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INTRODUCTION

Christmas '91 was a turning point in our family life. On Christmas morning my wife Glen and our two daughters, Jeni and Sarah and our son, Gareth, aged 10, 6 and 2 respectively were looking forward to the seasonal festivities. The tree in the corner of the lounge was full of colour and adorned with twinkling lights and chocolate surprises, waiting for the attack by excited children begging to taste the edible treats suspended from its branches. The presents under the tree included a new yellow bike for Gareth, gleaming and waiting for the initiation ride by an excited child. I suppose, in hindsight, this was the first insite we were to have indicating that Gareth was not quite acting his normal self. He didn't show the expected enthusiasm for his new toy and after a brief try he gave up on it and sat down on a chair. Perhaps he was still tired. Later that afternoon we all wrapped up warmly and went out for a breath of fresh air taking Gareths' bike along also. He peddled around merrily for a short while before wanting a little rest. At least he now seemed to be enjoying his new present. The rest of the holiday period we spent visiting relatives as a family does but, all too quickly we had welcomed in the New Year and it was time for me to go back to work.

During the following couple of months of 1992 a number of very subtle changes took place in Gareth which began to concern us. Firstly, he showed an unusual degree of restlessness, particularly at night when it was time for him to sleep. He had, up until now, been such a good sleeper and once settled he would typically sleep deeply until the next morning. However, he now began to get very upset and quite distressed when placed in his bed

at night. He would constantly sit up and cry until he was held once again. Once in your arms however he would quickly settle and fall asleep. The moment he was laid down he would wake up and cry. It was as if he had a 'tilt mechanism' inside him, which would wake him, as soon as he was placed horizontal. All this was assumed to be nothing more than a difference in his sleep pattern as he was growing. Perhaps the start of the "terrible two's".

It was a couple of weeks later when we caught a glimpse of Gareth as one of his eyes appeared to diverge from centre. This would happen for a split second and on closer inspection would appear normal. Over the coming days and weeks this began to happen more frequently until he had a definite, albeit mild, divergent squint in his right eye. Glen made an appointment for Gareth to be seen by our local doctor for his opinion and he eased our mind by telling us that he thought Gareth had a simple squint which was not uncommon in a young child. Such a squint was usually the cause of weak eye muscles resulting in a "lazy eye". We were somewhat relieved that it was nothing more serious. However, during the course of the next couple of months he had bouts of tiredness, with occasional vomiting. Glen took him to the doctor on several occasions during these sessions and it was eventually implied to her that she was being a fussy mother. We began to get more and more concerned but, nevertheless, we accepted the professional's opinion.

During school half-term holiday in the February of '92 we spent the week at Glen's parents' home on Anglesey in North Wales. This proved to be a turning point in Gareth's health. He became very nauseous and refused to drink. He would ask for food but when it was placed in front of him he couldn't bring himself to eat it. His behaviour was such that we felt the need to visit the local doctor whilst in Wales. After a brief check of Gareth the doctor correctly diagnosed constipation, and

prescribed the appropriate medication. Gareth did slowly appear to start to get back to his normal self, except for the continued disturbed sleep pattern. We began to relax slightly, hoping that things were now returning to some normality, and tried to enjoy our week long stay with grandparents.

It is amazing how the holiday seemed to pass so quickly and before long we were back home. However, in early March his condition seemed to deteriorate very quickly indeed. Showing total lethargy, he would sit and watch his favourite video over and over again in almost total silence. He began to mutter “my eye’s falling”, and he would lie with his head resting on a cushion. Our own local doctor at this stage was still insisting that there was nothing unusual going on. Eventually, at 8.00pm on Tuesday the 10th March 1992 at the insistence of a family friend who was also a nurse, we took Gareth to the casualty department of our local hospital 10 miles away and asked them to check him over. We detailed to them what had been going on during the last couple of months and what the doctors had previously diagnosed. In hindsight I feel that they too readily took these comments on board and were falsely led down the same route of investigation. Instead of jumping in with all tests, they took an abdominal x-ray and, sure enough, Gareth was well and truly constipated. He was admitted onto a ward and there followed three days of enemas and tube feeds. After all, he must have his fluids! What follows is a personal description of the hell, which was to break out before our very eyes.

Ken Booker
Cannock Chase, 2004

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CHAPTER 1

The Long Journey

It was 10.00am on Saturday 14th March 1992. The ten-mile journey to hospital was uneventful. The normal rush of Saturday morning traffic having to be contended with, giving my mind time to drift and wonder about 'how Gareth will be today'. Removing my overnight clothes from the boot of the car, I headed towards Ward 11 at Stafford District General Hospital. Glen had been there since Gareth's admission on Tuesday evening and she was showing signs of physical and emotional exhaustion. It was my turn to stay overnight in order to give her a chance to have a shower, sleep and recharge her batteries ready for the following week when I continued my work as a secondary school teacher. I was worried about staying since I have always had a dreadful fear of hospitals and more specifically needles! This was my first experience of a real hospital environment having successfully avoided contact with this section of the National Health Service all through childhood.

The ward was pleasant, colourful and very welcoming. The friendly smiles were comforting. However, as I turned the corner and saw Glen, I was somewhat shocked. She is a very loving mother and always has, and will continue to, put her family first. She was stroking Gareth as he slept in the cot beside her, cherishing every touch of his beautiful, tender face. She knew things were not right as only a mother does. How? Had he been ill in the night? Had the doctors said something? She looked totally exhausted. Gareth had not been any trouble; in fact, his apathy was the first indication of something being wrong. You should never ignore a mother's instinct as I did on that day. Glen was expressing concern about Gareth's progress, or lack of it, the fact that he had little energy or interest in playing. He could not even be bothered to open a "Get Well Soon"

card which had been given to him. My first regret in this whole episode that was about to evolve before me began here. I told Glen she was worrying needlessly and the fact she was so exhausted was confusing her perception. The doctors didn't appear too concerned; after all it was only a case of bad constipation he was suffering from. Enemas and tube feeds would soon solve the problem. Glen left the hospital, reluctantly, and drove away for that well earned time at home to rest and be a 'normal' mum for a while to our two daughters, Jeni then aged 10 and Sarah 6.

I settled down in the chair next to Gareth's cot holding him gently in my arms. He didn't talk much and what he did mumble was difficult to comprehend, he just seemed so tired. It was about an hour after Glen had left that the doctor did her rounds. She looked at Gareth and indicated that he was not improving as quickly as she had anticipated and explained that she would like to put some dilatory drops in his eyes to take a closer look. Gareth obliged with very little resistance to the drops, he simply didn't have the energy to fight. Whilst waiting for the drops to have their effect I phoned home and told Glen that they wanted to carry our further tests and perhaps she ought to come back to hear what the doctors had to say. Twenty minutes later Gareth and I were taken into the treatment room where, in darkness, his retina was thoroughly inspected. When the lights came up the ferocity of the blow that was about to follow could never have been anticipated. "There is quite a degree of pressure on the retina" the consultant stated. I knew this wasn't good news. She went on to say "If he had a temperature or rash I would suspect meningitis, however, in this case, and I hope I'm wrong, I think it might be a brain tumour"! We were taken immediately for an X-ray to try to get some form of confirmation on this. Carrying him to the X-ray department in the company of a young nurse, who was asking how I felt

was a strange experience. How I felt wasn't forefront in my mind at that stage, I didn't know how I felt, shocked, dazed, scared, concerned, even satisfied that they had at least found something and could now begin effective treatment. The X-ray apparently confirmed the doctor's worst fears. Within minutes I was told that an ambulance crew would be here shortly to transfer us to Birmingham Children's Hospital who could offer very specialised care.

I carried Gareth back to his cot where he lay, completely oblivious to the devastating news that had just been given to me. I threw all his clothes and belongings into bags so that we were ready to leave once Glen and the ambulance crew arrived. I could feel the rush of adrenaline kicking me into action. I picked him up from his cot and sat with him resting in my arms. Looking down at his beautiful features I couldn't help but think is this real? I just wanted to hold him and let him know things would be all right. He was not very conscious at this stage but I knew he would be responsive to touch and aware of the physical contact between us both. He was always a close, touching, loving child.

Glen arrived promptly, obviously concerned and somewhat shocked as I broke the latest news to her. We were both escorted into the doctor's consulting room where she informed us of her great concern about Gareth's immediate condition. We were now very much on automatic pilot. Whatever our emotions or feelings were at this time we had to go with the momentum set into operation by that dreadful discovery, and things were moving incredibly quickly. The doctor asked if we knew the precise location of Birmingham Children's Hospital, to which we replied "no". She promptly pulled out a local map of Birmingham, circled the hospital, and handed us the map. This actually became very useful over the coming days until we got used to the route. No

sooner had we returned to the nurses' station, the two ambulance crew arrived. I carried Gareth down to the waiting ambulance and we made our first steps into the vehicle. Our car remained in the hospital car park to be collected at some later date by a relative. The car was irrelevant at this time, just a lump of inanimate metal, we couldn't care what happened to it. Gareth had our thoughts 100%. We were joined in the ambulance by the ward Sister who accompanied us all the way to "The Children's". We later discovered this was because he was so critical and the intra-cranial pressure so great that he could have collapsed at any moment. The only chance he would have had at surviving such a collapse would have been for the Sister to insert a needle into his skull in order to relieve the pressure, thus allowing his automatic breathing mechanism to resume.

Birmingham had always seemed such a vast city and, despite it being only 20 miles from Stafford, I'd imagined it to be further away. We must have made it in record time down the outside lane of the M6 and along the Aston Expressway. As an attempt to distract our attention from the medical emergency the crewmember in the back with us was explaining the automatic speed limiter fitted to ambulances and the jerking you feel when it comes into operation at around 93mph. It was noticed on several occasions during the journey! Gareth remained in my arms all the way. Although he was conscious throughout the journey he showed total lethargy, almost as if he were peacefully drifting. The Sister kept a very close, but unobtrusive, eye on him throughout the journey. There we were, a 'normal' family in an emergency ambulance with a medical team awaiting our arrival at one of the country's leading children's hospitals. This always happens to other people, not us! How naïve can you get. There comes a time in life when the odds favour *you* as one of the 'other people'!

CHAPTER 2

The Surgery

On arrival at "The Children's" my heart sank. We had left a newly constructed hospital in Stafford with all the luxuries that came with a modern hospital and entered a corridor that seemed reminiscent of the days of Florence Nightingale. The fact that the walls contained a brightly coloured mural could not totally hide the old, dated, brickwork underneath. The fear and the severity of the situation suddenly struck me. "Oh Gareth, this is serious" I found myself uttering under my breath for fear of anyone else sensing my despondency. They say that first impressions are important, well my first impressions of the Children's Hospital were not good and, in fact were made worse on seeing the ward we were admitted to. Ward 1 was a general surgery ward Which consisted of one long, wide "corridor" with beds both sides and a nurse's station halfway down on the left-hand side. I must point out here and now that we were soon to discover what a fantastic and supportive nursing staff the hospital possessed. As a family we were quickly befriended and surrounded by some of the very best people in the field of medicine. Whether it be the highly dedicated and empathic neurosurgeon, the ward nurses who were able to support us often without words needing to be spoken or the junior doctors who always managed a smile despite being dragged out of their beds at all hours of the night in order to admit Gareth to a ward. I soon began to feel for these people who were doing a miraculous job in such pitiful conditions. So, the memory of our entry to ward 1 can be described in one word, mayhem. Saturday afternoon, visiting time and T.V's blaring away. I lay Gareth down in his allocated cot. He was motionless, apart from the steady rise and fall of his chest as he thankfully breathed. He made no response whatsoever to his new noisy, chaotic

environment. The Sister who had supported us on our ambulance journey handed over her responsibilities to the new staff and gave Glen a squeeze, perhaps out of empathy from one mother to another, as she left us wiping her moist eyes as she walked away. The ambulance crew, two nice guys and I suspect fathers, wished us good-luck and left. We later discovered that the crew had been in touch with the hospital to get an update on how Gareth was. A nice thought which I found quite moving. When the chips are down, there really are strangers who can show genuine concern and interest in fellow members of the human race.

The doctor on call arrived swiftly and checked Gareth over thoroughly. This fellow really brought us into the real world with a jolt. He was full of life, springy, semi-jovial and pleased that the answers we were giving to his questions fitted his text book scenario beautifully. "Don't worry" he announced, "We'll look after him and get him sorted, I'll just go and consult my colleague and be back in two ticks"! Oh boy, my first thoughts were "Is this comedian, in his yellow dicki-bow, having full responsibility for the life of my son"? Shortly afterwards he returned and explained the fact that they would be taking him down to X-ray for a CT scan and that the radiographer had been called in specially for this to take place as soon as possible. To the consultant it was already fairly apparent that Gareth had a severe collection of fluid in the cerebral region, which would require draining, and he went on to talk about the "simple" surgical method of relieving this pressure by inserting a "shunt". However, more detail could be provided once the CT scan had taken place and the plates analysed.

Out of preference, I carried Gareth down to the X-ray department near the main entrance to the building and placed him onto the bed of the scanner. He offered no resistance whatsoever; he was well and truly out of

the situation by this stage, his life was literally in their hands and the criticality of his situation was becoming more apparent seemingly by the minute. There was no need for them to sedate him as he was already so conveniently lethargic. The 10-minute scan ran with no stoppages, he was an ideal patient as far as the radiographer's job was concerned. We returned with Gareth to the ward to discover the staff has been playing musical beds. Gareth's cot was now positioned directly opposite the nurses' station. We soon caught onto the fact that the closer you were positioned to the nurses station, the more concerned they were about your condition. It was obvious that because of the seriousness of the situation they wanted to keep a very careful eye on our son without being too visibly oppressive or increasing our anxiety any further, if that was possible.

It must have been around ten that evening when we first met a young, confident man, dressed casually in a sweater and carrying a mobile phone (a relatively new form of communication even in 1993). He approached and introduced himself as Mr. Flint the Neurosurgeon that was "on call" this weekend, although he was actually based at the Queen Elizabeth Hospital in Birmingham and not The Children's Hospital. He was to be responsible for Gareth and he made it crystal clear that the priority at the moment was to ease the pressure that was trying to force Gareth's skull to explode. He showed us the results of the CT scan, taking time to educate the ignorant on the intricacies of interpreting a mass of black, white and grey areas on a sheet of acetate clipped carefully to the light box. It didn't take long to appreciate 'the problem' within Gareth's head. The huge grey area, which I queried as being brain, was in fact cerebral fluid. The increased pressure of this fluid was crushing his brain. This was causing parts of his brain to shut down and he was in the final stages of his empathic system closing down also. Quite simply his brain would

shut down the part that ‘told’ his lungs to inflate and ‘told’ his heart muscles to contract. He was, in fact, dying. The question now was how much time had we got before intervention was needed. "How quickly did we feel he had deteriorated in the last few hours?" was an impossible question the neurosurgeon posed for us to answer. At that moment in time the emergency operating theatre was in use by surgeons operating on a child who had taken a fall which resulted in a pencil piercing his skull. It wasn't known how long this surgery would take to complete and Mr Flint thought it preferential to have a fresh theatre team the next morning rather than operate on Gareth with a tired team that evening. Our hesitancy being able to specify how much Gareth had deteriorated that day led the neurosurgeon to correctly interpret it as meaning our son's condition was indeed going downhill rapidly. It was decided to see what sort of condition the theatre team was in on completion of the existing operation before making a final decision. Mr Flint left but returned not long afterwards to tell us that the present operation was due to finish sooner than expected. Fortunately for us the pencil incident had not been as complex as was first envisaged and now Gareth was to be taken down to theatre at around midnight. This man oozed confidence; something about his manner allowed you to be carried along with him in this array of positive thinking.... I knew Gareth couldn't be in safer hands. This wasn't to say that we didn't fear that Gareth may not survive the surgery that night, but simply that if he could be saved then this man was the person to do it!

The porter together with theatre trolley arrived creating some inevitable disturbance in the silence of the night. Gareth was, of course, completely unaware by now but we walked alongside him to theatre anyway. The route included a trip down the ‘tunnel’. This was a section of clear perspex-covered walkway linking two separate, very old, buildings. The poor tarmacked way

would have made it difficult for a BMW to give a smooth ride so a hospital trolley had no chance. I felt for Gareth with every single bump wondering just how painful it must be in his head. Eventually we reached the theatre doors and only one parent was allowed in to the 'pre-med' area. Fortunately Glen had the strength to do this, my fear of anything to do with hospitals was reducing by the minute but I wasn't ready yet to be thrown into needles, and all the fear that an operating theatre induces. I can't begin to explain my feelings as I watched my son go through that pair of doors in the genuine knowledge that he may not come out alive.

Glen and I walked back to the ward together at a loss of what to do. I suppose this was the first opportunity since arriving at The Children's where the whole situation had time to impact on us. It seemed unreal. Our son was now in an operating theatre undergoing brain surgery in order to save his life. He was so critically ill that the surgeon did not feel he would make it through the night without this operation! We sat by his empty bed in the quiet of the sleeping ward and waited. Eventually after what seemed an eternity but was in fact closer to an hour later we had news that Gareth was out of theatre and would be back on the ward shortly. We could allow ourselves that first slight sense of relief in the knowledge that at least he had survived surgery. The first of what was to become many hurdles had been successfully accomplished.

The first indication of the imminent return of our son to the ward was hearing him crying. The silence of the ward was broken as the theatre trolley appeared. It was wonderful, we hadn't heard him offer any resistance to what was being done to him for quite a while now. His crying meant he was once again aware and capable of expressing his feelings. We met him and he immediately recognised us, this was a good sign indicating that possibly the brain hadn't been damaged

by the extreme pressure and that it had been caught just in time. It was wonderful to have him back within physical reach. The ward staff organised infusion pumps, oxygen level alarms and all the paraphernalia that comes with post-operative treatment. We had to put all our trust in the ward staff, and we quickly learned to gain confidence in their ability to give Gareth the best care available. Gareth just lay there taking in the whole scene, making no noise now he knew mum and dad were around, but visually more alert than he had been for weeks. He remained awake for 36 hours, never once closing his eyes for a nap. It was almost as if he could not believe he was back in this world and every minute for him felt so good. When I think of the pain he must have had in his head resulting from all that pressure of trapped fluid it must have seemed like heaven to him to have a relatively pain free existence. The 'peace' he had now regained seemed measurable. He would smile and suck his thumb. His eyes skirting around focusing on anything his peripheral vision could accommodate. I held his hand throughout the remaining hours of that night and persuaded Glen to get some rest ready for the difficult times ahead. I felt so close to Gareth in those hours before dawn arrived.

At this early stage in Gareth's initial treatment, both Glen and I stayed at the hospital whilst Jeni and Sarah were looked after by my parents. By the time I collected the girls and we'd arrived home I had very little energy or time for either of them, but they seemed to understand. I often wonder what really went on in their minds during this period. They must have been so confused despite us trying to explain things to them. We had made a conscious decision very early on that if we stood any chance of making it though this as a family there could be no secrets. They were both fully in the picture as to the seriousness of the situation with Gareth. I remain convinced that they were put through more

emotional and physical turmoil than Glen and I. At least we were there with Gareth at every decision and action, we were actively participating in his treatment, which in itself was treatment for us. Jeni on the other hand, who was barely ten at the onset of Gareth's hospitalisation had to be 'mother' to her sister Sarah who had just had her sixth birthday. The one painful memory that still stings the consciousness today was watching Sarah having to be 'ripped' out of her mother's arms screaming uncontrollably at the end of hospital visiting as my parents took both girls home. Jeni was simply having to brave it out, putting her arm around her little sister and telling her... "it will be all right, I'm with you"! She needed to cry too and yet she was deprived of this safety valve early on. Both my wife and I felt we had little choice but to stay with Gareth in those very early days until he was stabilised and his future treatment, if any, was considered. There simply wasn't emotional room for us to be parents to all three children at the same time when the needs of them were so different and time simply not available. In hindsight, I'm not sure we could have done anything different at this stage. Having a critically ill child certainly impacts on all members of the family and no doubt there would be consequences of our actions appear as the weeks and months went by.

The surgical team had satisfactorily inserted a shunt into Gareth's head in order to relieve the pressure. This gave everyone a little breathing space where the next stage of treatment could be assessed. We knew Mr. Flint had a great deal of concern for Gareth as he tried to explain the next course of action during our follow-up meeting with him. The next priority was to discover the nature of the tumour, which lay in the pineal region of Gareth's brain. Was it benign or malignant? We prayed for the first. Was it a slow growing type or fast? Once again we prayed for it to be the first. The only option was to carry out a brain biopsy and the risks and

possible consequences of surgery were detailed to us, no holds barred. We continue to be thankful for the forthright honesty expressed by all of Gareth's medical and surgical teams. We were given time to absorb all the facts and were then able to make rational decisions. The fact that we were given some control over the situation was critical to us, after all at the end of the day it was our son and we were the ones ultimately responsible for him. We were told that it was a complex biopsy that Gareth needed and that Mr. Flint was considering two possible approaches of entry into this almost inaccessible part of the brain. Each entry point held its intrinsic dangers ultimately leading to potential brain damage and ultimately death. I had an insatiable appetite for knowledge. I needed to try to understand everything that was planning to be tackled in theatre and come to terms with the risks involved. Mr. Flint suggested to us that when Gareth had recovered sufficiently we should try to enjoy a few days at home, meanwhile he would do some reading on new innovative surgical techniques specific to the central brain region. How can you not trust a man who tells you he will read up on the subject in the bath, where he does his best thinking, and make a final decision as to the procedure to use in Gareth's best interests!

Gareth recovered very quickly from the initial shunt operation so, nine days later, on the 24th March 1992 we were allowed to go home and have a few days of some normality thus allowing us as a family to come to terms with the situation. The feeling of escape from the drudgery and mental taxation of being in a hospital 24 hours a day caring for a sick child is indescribable. I remember vividly only a few weeks earlier viewing one of the BBC's "Hospital Watch" broadcasts and saying to Glen "How on Earth do the parents of such seriously ill children manage to carry on?" Well, fate has an evil way of testing the human resolve and, although it sounds very

clichéd, it's true to say you just cope. Life is put on hold as you take each day, even each hour, a step at a time.

Here was our first opportunity to get home and become a family of five once again. The feeling was good but we knew it would be short-lived. Gareth was a different child to two weeks before, although his speech was slurred and his stance unsteady, he was very active. It was wonderful to see him wanting to run in the sunshine with his sisters giving him every support and encouragement. If he was to make it then it was going to be Jeni and Sarah that would see to it. They got him moving in ways that got observing adults cringing. Was this child now dancing to pop music, playing "Twister", and rolling around on the floor with his sisters the same boy who had undergone brain surgery only days previously and the boy that was now fitted with a "shunt"? Gareth had made his point. It was as if he knew how close he had come to dying and was now determined to enjoy his life and face each new challenge one day at a time. I suppose one could say we were fortunate in that he was unaware of the long and painful road ahead. Right now he was happy and having fun! So too were the girls! Sarah was a fun playmate for Gareth and, as for Jeni not only was she his best friend and playmate she also became a natural born physiotherapist to him. She got his limbs into positions no one else could imagine and all through play. He loved it! She was a ten year old going on twenty. The months ahead were going to force her to grow up more quickly than was fair for any child to have to handle.

We knew this normal family life could not go on for long. Gareth was to return to Birmingham Children's the following Thursday 2nd April 1992 ready to undergo a biopsy on the 'mass' which was still causing a blockage within the centre of his brain. We knew returning to hospital was going to be so hard. It would have been so easy to fool oneself into thinking that there

was nothing wrong with him now and that the shunt was all that was needed. After all he was starting to run around again and he was constantly singing, reciting nursery rhymes, laughing and, more to the point, making others around him laugh; he adored having an audience. The day before returning to hospital the five of us went to the local park armed with a friend's video camera. This is the first tangible record we possess of Gareth showing, through sound and vision, that he really was enjoying life. That day in the park with the sun shining and the three children playing together will always bring tears to my eyes. It was the recognition of what normality should have been like and the acceptance that he was about to undergo major brain surgery and all the fears and dangers that carried with it. Quite simply seeing him playing whilst thinking he may be dead within the next 48 hours did tend to focus one's perspective on life!

Those 48 hours passed very quickly and before long we were on our way back to hospital. Gareth never had any qualms or fears about entering 'The Childrens'. This time he was conscious, content and very alert, a shocking comparison to a couple of weeks earlier. He greeted the nurses in his pleasant, charismatic manner which, as we were later to discover, was to be his hospital trait. He quickly settled into his new home for whatever length of time the future deemed necessary. The playroom was one of his first ports of call. I'm not sure what the attraction was since many of the toys there were broken or incomplete but he was to spend many happy hours there over the coming months. I lost count of the number of storybooks we read to him during our stay. He truly loved being read to and got wholesome joy from picture books. It was, however, with great trepidation that I entered the hospital that bright Thursday morning. We were being admitted in preparation for the brain biopsy that was planned for the

following day. There was no question in anyone's mind that Gareth was so much better than he was a couple of weeks ago and we could see positive signs of improvement daily. There was always the hope deep in my mind that perhaps he was making such brilliant progress the biopsy would not be required and that he was now "better". Of course this was not the case but there are times in life when you just need to bury your head and wait until "it" goes away. This was one of those times! He was booked to go into theatre the following afternoon. We had to make today as fun as possible despite the torture that was going on inside us.

Glen spent the night on a campbed erected at the side of his cot on Ward 1 and I slept in a room which, in a previous life, was an excuse for nurses' accommodation quarters. A room which left one feeling desperately isolated and lonely did not help to maintain one's optimism which was so desperately needed in order to cope with the imminent uncertain future. However, we were grateful for a bed within a five minute run of Gareth's cot, and I would unquestionably have slept on the hospital steps if there were no other options available to us. That morning seemed to go on forever but eventually one of the nurses came to give Gareth an oral pre-med. The porter arrived shortly after but was not needed since Glen preferred to carry Gareth to theatre. The simple option offered by the staff of carrying your own child to the operating theatre was so important to us as it meant we still had a degree of control over the situation and we were made to feel that we were still actively involved in the treatment of our son. At 12.35pm on Friday 3rd April 1992 Glen, with a drowsy Gareth huddled in her arms, walked through the double doors into the anaesthetic room. I was torn. I wanted to be with Gareth but I knew at this stage I hadn't fully acclimatised to the hospital environment. I would never have been able to hold it together as Glen did. She would

have been such a comfort to him in those few seconds before he fell asleep. I went back to Gareth's now empty but warm cot. Glen reappeared at 12.48. Why did I write these times down? Perhaps for me to look back on and realise this was reality. A terrible living nightmare that one would never be able to wake up from. We were warned that it would be a long operation possible four hours or more and it was strongly recommended that we went and got some fresh air and food.

The traffic outside the hospital main entrance was as hectic as ever. A feeling of irritation and anger was evident within me. There were all these people going about their normal daily routine. Lunchtime on a Friday, office workers going for a pub lunch, laughing, when my son was undergoing major brain surgery. The whole thing seemed surreal. Tesco store was immediately opposite the Children's Hospital, a deliberate ploy on the part of Tesco planners I cynically thought since a great number of the customers there seemed to be parents or relatives visiting sick children and simply looking for a half-decent meal. We sat in the restaurant and played with sausages and chips on our plates. Neither of us really wanted food but we were aware of the immense drain on all our existing energy reserves and knew that our adrenaline levels would need to remain high for quite a time yet so we tried to eat. I suppose we were away for forty minutes or so before we felt we needed to go back and "be there" just in case. It was around 2.30pm when Geraldine greeted us. She was our Oncology Liaison Sister who was on Gareth's case since the day of his diagnosis. We were all to become greatly dependent upon her to seek clarification on medical details, on our behalf, whenever the time arose. We have a great deal of respect for her and the role she played in Gareth's life. Gareth was her little "Mr. Twinkle", the name he acquired when she asked him to recite a nursery rhyme in order to check his cognitive

development after the initial traumatic surgery he had undergone. She visited us specifically to tell us that things were going fine and that she had been into theatre to look at the procedure Mr.Flint was doing. I felt a little jealous as I wanted to see exactly what was happening and wished that the whole thing was being videoed. I realise that this may sound gory but it was my son in there and I wanted to know *everything*. Geraldine also told us that because everything was going so well, Mr.Flint was opting to carry on the procedure for longer than planned in order to give Gareth the best possible quality of life. It was going to be a while yet before he was out of theatre. At 3.30pm the porter came to collect Gareth's cot and take it to theatre. Great, this was a positive sign that he would soon be back with us. It was finally 7.00pm however when a nurse came and asked Glen if she would like to come with her to collect Gareth from theatre. My eyes watched those ward doors and my emotions waxed and waned at every noise until finally, at 7.25pm, the banging noise resonating down the corridor was Gareth's cot arriving complete with our son.

He was lying on his side in a recovery position with drains and monitoring equipment attached to him. He was not looking as bad as the imagination had led me to expect. The horse-shoe mark on his forehead was a result of being supported face down for several hours whilst the neurosurgeon did his job of surgically entering my son's brain via the base of his skull. This superficial bruising on his face was soon to go down. It was to be another long night of careful monitoring and observation as the anaesthetic started to wear off. Although he was on morphine to reduce the pain, and steroids to minimise the risk of swelling (a consequence of brain surgery and a major danger to be contended with) Gareth was surprisingly alert. Expecting his whole head to be bandaged, I was amazed to find he had just one dressing

down the entry point covering the stitches. It was so good to know he had come through the ordeal and was safely back in our hands. Later that evening Mr. Flint came down to Gareth's bed to speak to us. His words will stick in my mind for the rest of my life. Everything had gone extremely well and he had "...evacuated all visible signs of tumour...". Although the main aim of the operation was to obtain a biopsy he did promise that he would endeavour to remove as much tumour as possible if the opportunity arose. We had hoped for *some* removal of bulk mass but had dared not consider the possibility of having total removal of visible tumour. My heart pounded as he told us this news. It is the closest I have ever come to kissing a man with a beard! He had given us the best news possible at this stage in treatment. Gareth was not out of danger but he had been given a good head start in the fight thanks to the neurosurgeon's skills. He went on to tell us that the surgery he had performed had been very invasive and, that if he were carrying out the same operation on an adult he would have halted much earlier but things were going so well and the bulk was coming away quite readily. Children are far more resilient and seem to bounce back more rapidly than adults. It must take tremendous courage on the surgeons part, and I suppose a certain degree of luck, to be able to push things to the limit in order to achieve the best survival chances. Anyway we remain indebted to Mr. Flint for giving Gareth the opportunity to live a good quality of life in the months which lay ahead after surgery.

CHAPTER 3

Post Surgery

The day after his operation, Saturday 4th April 1992, Gareth was making such good progress. It was difficult to believe the surgery he had undergone just a few hours earlier. Glen's mum and dad visited us at the hospital and they were obviously pleased to see their grandson alert and communicative. The following morning Gareth was still asleep at 7.00 so both Glen and I decided to nip up to the hospital canteen for breakfast. It was a rare opportunity to spend twenty minutes together away from the intense atmosphere of the ward. When we returned Gareth was still asleep but the ward Sister told us that he had been twitching and she thought that he may have been fitting. His temperature was checked and found to be slightly raised. There was an initial fear of meningitis and wheels were quickly put into motion to investigate the cause (apparently meningitis is always a risk after brain surgery.) During surgery the brain is exposed to the open and, even in the sterile confinement of theatre, there is always the danger of bacteria entering directly. The neurosurgeon was contacted and he prescribed Phenytoin for the fitting but ordered the staff to hold back on the antibiotics. He was of the opinion that the cause was more likely to be "chemical meningitis" resulting from surgery and that antibiotics would not assist here. He asked that a sample of cerebral spinal fluid (CSF) be sent to the labs for urgent examination. Later that afternoon Gareth was wired to a cardiac monitor and the SHO injected an IV dose of Phenytoin. This anticonvulsant drug had to be carefully calibrated taking into account his body mass and injected very slowly. Throughout the injection the heartbeat was monitored very closely for any change in rhythm. Fortunately, Gareth showed no side-effects to this medication. A little while later we were called into the

treatment room for Gareth to have the CSF sample taken. The normal method of sampling the CSF would have been to carry out a lumbar puncture procedure. Gareth, however, had a perfect access point via the internal shunt in his head. I held Gareth in a sitting position whilst the doctor inserted a needle through his scalp directly piercing the shunt reservoir. I was amazed how calm Gareth remained throughout the whole procedure. I assume he never really felt anything, but the thought alone was enough to make me flinch. However, like Gareth I never moved and just held his head firmly against my chest. Once the needle was in place a sample of fluid was tapped off. The whole process took a matter of minutes and we soon returned Gareth back to his bed. We now had an anxious wait for the labs to process the sample. It seemed like an age but in fact it was only a matter of hours before we received feedback on the sample of CSF. Although his white cell count was up on normal it was nowhere near the figure they would have expected in the case of bacterial meningitis. It appeared that Mr. Flint was correct in his diagnosis of chemical meningitis resulting from surgery. It was simply a watching and waiting game. Gareth had to stabilise the chemical imbalances himself. His body had to be left to repair the damage and upset which had been caused by surgery. All we could do was keep his temperature stable with Calpol and give him time.

Once again, his body's determination to fight back and regain full health left us all quite amazed and the following Thursday, 9th April, he was discharged and allowed to go home. It was so good to be in the home environment once again. The major worry about surgery was now behind us. Other worries however came to the forefront of our minds. Concern for Gareth's well being was ever present and having the confidence to relax a little took some getting use to. The next few days though were ours, as a family. We spent the Saturday at

Twycross Zoo. It had been years since I'd been to a zoo and the children loved it. All three of them revelled in the pony rides and Gareth took great pleasure in the visiting the monkey house. I think he had a monkey streak in him somewhere down the line! We have many photos in our albums of that happy day. In fact from about that day onwards we must have spent a small fortune on processing films. We knew we had to treasure and record as much of Gareth's life as possible both for our own sake and the girls. We were at the beginning of a long hard battle, which was grossly biased against us before we even started. We simply had to make the most of the positives and try to ride out the negatives. This proved very difficult at times, but we continued. The girls saw a new Gareth. It was as if he had been given a new lease of life, which I suppose in hindsight is exactly what he had been given. He loved his two sisters dearly and spent many happy hours playing, teasing, singing, dancing, cuddling and kissing with them. It was a pleasure to see such happiness in our family once again.

Wednesday 15th April brought about our first clinic appointment at The Children's. Despite the doctors seeing patients non-stop the waiting went on and on and on.....it was just like watching paint dry! The real frustration was the fact that we wanted to make the most of our new found freedom and not have to spend the best part of a whole day in clinic. However, it was essential for him to have his regular checks and anyway we would be put in the picture as to what further treatment would be needed. It was during this clinic visit that we were informed of the biopsy results. Previously Gareth's consultant, Dr. Mann, had made it clear to us that we should not be too optimistic on the grade of tumour. Sadly the 'worst case scenario' was now to be confirmed by the labs. The tumour Gareth had was confirmed to be a pineoblastoma. The success rate for treatment was currently around 20%. The odds were firmly stacked

against him but we were now more determined than ever that he would get through this. We were told that the next step was for an MRI (Magnetic Resonance Imaging) scan to be carried out in order to get a very detailed picture of the tumour remains. A phone call at home later that evening from Dr. Mann informed us that the MRI scan was booked for Monday 27th April and that he was to be admitted to Ward 5 on the evening of Sunday 26th April. We decided to make the most of the next few days at home and went out as a family unit at every opportunity. During those days at home Geraldine rang to check up on things. It was good to know that ‘the team’ approach to Gareth’s treatment was now firmly established. It was important to us all, and in particular to Gareth, that everyone played an active role in the fight to give him the best quality of life for as long as was feasibly possible. At this stage we were fighting for full recovery and a return to normality. In hindsight, perhaps an unrealistic goal, but Gareth looked so well and at this stage it was easy to be fooled by appearances. One of the many frustrations we had was trying to explain to people that he was not ‘out of the woods yet’. Yes he looked much more like the Gareth we all loved and knew but he was a long way off the finishing-post to full and complete recovery.

CHAPTER 4

Chemotherapy

On Monday 27th April Gareth was scheduled for full blood tests, MRI scan at The Nuffield Hospital in Birmingham followed by a lumbar puncture on his return to The Children's Hospital. On Tuesday he was to have a kidney function test to determine the efficiency of his kidneys before any chemotherapy treatment could be administered. The blood results looked okay with an Hb of 11.2 and a white cell count of 6.7. This was the first set of results I really began to note down. It was only now that I started to ask questions and do my homework by reading up about blood counts and, later on, the chemotherapy process itself. I felt like a sponge needing to soak up as much knowledge as possible. I think it helped me to maintain some degree of control of the situation. It wasn't long before the nurses were delivering his blood results to me as they received them, knowing that I wanted to be kept informed. This simple act made an unbelievable difference to us as parents. Glen was not so desperate in wanting all these results, she was very much maternalistic just being a loving mother to her son. Perhaps it was a 'man thing' in that I felt the need to actively 'do' something. Hence all the collecting of data, plotting of results onto a graph in order to try and see patterns of his response to the various chemotherapy drugs, etc. Patterns did become evident and it was useful to know what to expect in the run up to each chemotherapy cycle. I also thank my wife for letting me bury my feelings in these acts without criticising or judging me. I think she knew it was just something I had to do to feel involved. The important point here is that as far as the nursing staff are concerned we were always made to feel a part of the team and never treated as simply parents who were getting in the way. They all accepted the fact that it was our son they

were carrying out all these medical procedures on and we had a vested interest in everything they did. I cannot thank them enough for the understanding they showed us.

At 8.30am a taxi arrived at the hospital entrance to ferry us to The Nuffield Hospital to carry out the MRI scan. Gareth had already received a dose of pre-med. When we arrived at The Nuffield we were promptly led into the scanning room where I lay Gareth down on the bed of the scanner. He was well sedated by now and completely restful. The procedure was explained to us and we were allowed to be in the immediate vicinity as the scan was carried out. The Head of Radiology, Dr. Chapman, realised my teaching field was physics and so explained the process in great detail and we all viewed the “live” scanned images on the monitor. This again was so helpful in coming to terms with the reality of the situation. The scan took around an hour and a half to complete. We could see for ourselves the tiny remaining evidence of tumour, which lay in the pituitary region and measured around 1cm at its maximum dimension. Excellent news to us considering the neurosurgeon had removed a tumour which he described as the size of a small orange. This was the evidence we wanted, unequivocal confirmation that he had successfully removed the major bulk of tumour. We returned to The Children’s reasonably contented, with Gareth still out cold!

An hour later Gareth was just beginning to come around from the sedation when he was called into the treatment room for the junior house doctor to carry out a lumbar puncture. We held Gareth in the foetal position whilst the SHO (Senior House officer) got a CSF (cerebrospinal fluid) tap in first time. The clear liquid dripping from his spine was collected in a small specimen container and sent off to the labs. It was all over in a matter of minutes and Gareth seemed none the

worst for it, fortunately. The insertion of a 'central line' was the next important step for him since this would allow the infusion of his chemotherapy drugs directly into his bloodstream thus preventing the anguish and pain which numerous IV injections would cause. Besides that there is a limit to the number of needles you can put into tiny veins before they 'tissue' and ultimately collapse. So, we were relieved to be told later that afternoon that a 'central line insertion' operation was planned for Thursday in order that his chemotherapy could begin on Friday. We were allowed home on Wednesday but had to be back for theatre by 4.30pm the following day. I cannot explain just how good it was to get home, even for just 24 hours, and remember what it was like to be a complete family again.

The following day we arrived back at the hospital earlier than instructed only to be greeted by the Ward Sister and a porter waiting to take him down to theatre. We barely had time to dress Gareth in his theatre gown before he was being whisked down for his central line operation. It was about an hour and a half later when he returned, drowsy but well. He slept well through the night.

The following morning, Friday 1st May 1992, he was happily sitting up in bed when the doctor's appeared on their rounds. He showed no concern whatsoever for the central line or "wiggly" as they were commonly referred to by staff on the ward. We were the ones initially very protective of the central line, concerned that he might pull it out, accidentally of course! We need not have worried, to Gareth it was a new part of him. He never showed the urge to pull at it or attempt to remove it, as some children did, successfully in one case as I remember. It was explained to him that his "wiggly" would mean he no longer needed so many needles in his arm and that his medicine could be given through it. To this day I still do not know

how a child of two and a half could possibly comprehend all the things that were being done to him, but he was so at ease with the whole ordeal. He accepted his life for what it was and really showed us adults how to live life on a daily basis. Gareths new “wiggly” had two lumens one red and one green, this gave a ‘spare’ in case one line blocked at a future date. He soon named them “Tom & Jerry”. Tom the red, Jerry the green. The nursing staff would always allow him to choose whether they used Tom or Jerry for each injection they had to administer. Silly, childish, but what a difference this simple act made to his morale. Even at the age of two he was being given choices thereby subtly letting him have some control of his own body. This was fantastic to see and frequently became a source of great laughs as he teased the nurses by changing his mind at the last minute. What a joker he came to be!

The doctors agreed that he was to have his first course of chemotherapy administered later on that day. This was to be a quite gruelling course of chemotherapy. We had seen Dr. Mann a few weeks previous and she had made it crystal clear to us that the protocol they were recommending for Gareth was very intensive, but that they felt it would be the only chance to combat the type of tumour he had. A ‘very low survival rate’ is a phrase that stays in my mind from that initial conversation. She suggested we went away and thought about the prospect of putting him through such an aggressive protocol. The decision was already made however in our minds because the alternative was certain death within, potentially, just a few weeks. We had to give Gareth every fighting chance and as long as he was able to bounce back and enjoy the life he had, we would persevere with the treatment. The ‘American Protocol’ was the chosen chemotherapy schedule which basically consisted of a 13-month cycle of a combination of chemotherapy drugs on a 14-day rotation. Nothing can

describe the apprehension at 1.35pm on that Friday 1st May 1992 when the very first dose of chemotherapy was given, a Vincristine 'push' together with an antiemetic (Ondansetron). I can distinctly visualise the environment at that time and remember thinking "Okay son, this is it ... Day 1 of a long uphill haul". Sitting watching as someone injects your child with a potentially lethal cocktail of drugs evokes feelings which are impossible to describe. There were an awful lot of "What if's" going through my mind at this stage in the proceedings, but deep down I knew we had no alternative and I had never doubted the ability of the Oncology team. We were undoubtedly in the best possible place at The Children's. The infusion of Carboplatin was to commence at 4.20pm on the same day. This was to be a long evening, watching and waiting for Gareth's body to begin reacting to the toxins which were being forcibly pumped into his bloodstream. To my surprise there was no sudden reaction. Gareth went to sleep at the usual time that evening and I stayed with him by his bedside throughout the night. He awoke at 2.00am then dozed again until 6.00am. He was now very alert but refused his drink and toast and his bed and nappy were soaked. This was a good sign showing that all those fluids being pushed in were passing through his kidneys and being excreted as one would wish. Today was also the start of nappy weighing, yet another role which we were pleased to be actively involved in. We maintained his fluid input/output chart in partnership with the nursing staff. Then quite suddenly at around 8.00am he started to vomit. He showed little upset and simply said "me spit into dish....". He was so calm and laid-back by it all. I know if it had been me in his position I would have wanted so much sympathy it would have been embarrassing. An antiemetic was injected and by 8.30am he was happily sitting playing with his 'Duplo Zoo'. Another dose of Ondansetron at 4.00pm and we were

allowed home. We picked up a supply of Ondansetron in tablet form from pharmacy to administer at home for the next day or so until the nauseous effects of chemotherapy wore off.

It was during this period I found the need to research more thoroughly into the chemotherapy protocol. I had to know what the effects and side effects of the drugs were if only for my own peace of mind. To this aim I read a few text books which were available on the ward and noted down key points of which sample extracts from my diary are shown below:

Cis-platin - both an ototoxic and neurotoxic drug. Ototoxic effect being temporary tinnitus and temporary or permanent hearing loss. The neurotoxic effect was deemed to be reversible upon discontinuation of the drug.

Methotrexate (MTX) - excreted primarily by the kidneys, acute renal failure risk due to precipitation in renal tubules and ducts. Risk reduced if brisk diuresis maintained and urine is alkalinised. Conjunctivitis risk. Toxic levels of MTX found in tears of high dosage patients.

Vincristin (VCR) - does NOT affect normal bone marrow, causes peripheral (progressive) neuropathy with continual use, loss of Achilles tendon reflex and knee jerk are early signs of vinca neurotoxicity. Process reversed over weeks/months if drug is stopped.

Very scary facts but they crystallised within me the importance of the follow-up medical checks. The reasons why we had to test his nappies for pH value during MTX courses, why they forced huge quantities of saline through his kidneys etc, etc. Treatments and following actions were making sense. If I understood

My Grumpy Thumb

why they were doing these things then I could confidently support Gareth, knowing that everything that was being done was for his benefit. I had to feel I still had some control of the situation, albeit in a very small way.

CHAPTER 5

Oncology Clinic

Wednesday 6th May and it was off to Oncology Outpatients Clinic. The doctors were all very pleased with Gareth's progress to date. We took him for the standard simple thumb-prick blood test and afterwards, as usual, he requested a smiley face be drawn on his plaster. The phlebotomist readily obliged. Gareth was happy and contented and we shortly left for home. Oh how we loved those rare, quick hospital appointments! The following morning his temperature rose to 38.2°C and, after ringing the hospital, we were back in Oncology Outpatients at 2.30pm being connected to an infusion pump for hydration and a course of IV antibiotics. He was admitted to Ward 8 (dialysis unit), since they were the only ward with a suitable vacant bed for him. Gareth spent the night in a small 3 bedded area and Glen spent the night in a chair next to him. After what seemed like a very long night the following day we had the luxury of being moved into a single room. It was indeed a luxury that we wished could have happened more often. A room with en-suite facilities and a folding bed conveniently set up permanently beside his bed. This really was a luxury as we were used to struggling to erect a camp-bed every night and trying to squeeze it between beds in a crowded ward. Despite this lack of space the nursing staff never once complained that us 'parents' were in the way. Privacy however didn't exist apart from the partial drawing of a curtain between patients beds. Despite being surrounded by many people in this huge hospital I began to feel so isolated, feeling so alone. Looking back on that day it was fairly obvious that it was a very low point in my life. I was depressed at the whole situation and I was also both physically, and emotionally, drained. I was very distant with Glen and didn't particularly want to communicate my feelings to

her. Later that day in our wonderful private en-suite room we argued and both became very upset, all in the privacy of our own little world. Glen left the room and, an hour or so later, returned with one of the nurses we knew from the oncology ward. Glen had been able to confide in her and she had received comfort and moral support. I was jealous. I was angry! I was desperate for a shoulder to cry on too. She had aired her thoughts and vented her anger on a person willing to listen. I did my crying in the room, alone, as Gareth slept. However, emotions were soon to be buried once more as we continued the fight against Gareth's illness. Little did I realise at the time that this festering anger would find an escape route later on in my life!

During the nights that I stayed at the hospital I looked forward to the period which all parents enjoy. Once Gareth had settled down for the night and was sleeping peacefully I would leave his bedside and take the opportunity to grab a snack from the vending machine and sit on the steps of the hospital watching the world go by. It was not unusual for me to be sitting in the cold air at two in the morning just being grateful for the safe passage of yet another day. I wouldn't stay long for fear that Gareth would awake. Typically, I worried needlessly. I would return to look at his resting body and continue to be amazed and so proud of his resolve. He had cancer, so what! To him it was no big deal. He'd accepted what life had thrown at him and carried on regardless. I loved him so much and couldn't even consider what life would be like without him. I would not entertain the thought. Whilst he was willing to fight the battle against his cancer so valiantly how could I even contemplate the possibility of failure. No, we were all going to come out of this one day!

Thursday 14th May his Hb count was falling rapidly, presently 8.7 with a white cell count of 2.9, zero neutrophils and a platelet count of 11. As expected he

was given a platelet transfusion. Two days later his platelet count was up to 50 and Hb up to 9.0 but still zero neutrophils. He was completely open to attack from his environment. Even his own body's bacteria could set off an infection at this stage. With zero neutrophils his body's natural defence mechanism was out of operation. He was given a blood transfusion to help boost his Hb count still further and then taken off his drip at lunchtime. It was a beautifully sunny Saturday and Gareth and I were allowed out of the hospital for a short while. We walked to the nearby shops and then had a little picnic in a pedestrianised area of the city. This gave us both such an incredible feeling, a microcosm of normality. Gareth looked so relaxed and content sitting in the sunshine wearing his cap, and I was so grateful for the opportunity to be a 'normal' dad for that short period of time. The memories of that day are cherished within me and I gain comfort in the knowledge that no one can ever take those treasured moments away from me. We returned as promised, despite the temptation to go 'absent without leave', and were back on the ward for tea at 4.00pm. That was a wonderful escape for a little while!

The following morning we were allowed home. Another lovely, sunny day. Gareth had a wonderful time in the back garden with waterplay activities. It is when you return home that exhaustion sets in. As soon as you inhale that first deep breath of 'home air' you realise just how tired you are. Being a caring parent in hospital is unbelievably tiring, mentally as well as physically. When your child is very ill, emotions are on a continuous roller coaster. There is no way you can step off it, the feelings of motion sickness are ever present but you have to remain positive and focused on getting back to a normal family existence as soon as possible. This was our ultimate goal in life. Gone were the days when it was my ambition to have good career prospects,

a nice house or a new car. I wanted the thing in life that most parents took for granted which was the best of health for all of my children. We would fight for as long as need be in order to fulfil this ambition.

A phone call at 9.30am the following day from the hospital triggered the next step in treatment. Gareth was to undergo the second course of his chemotherapy cycle later that afternoon! At 3.00pm we arrived at The Children's to set his pre-hydration going. This was to make sure he had plenty of fluids in his body before it was hit severely by the chemotherapy drug Methatrexate (MTX). The first problem arose at 5.00pm when it seemed that one of the lumens of his central line was blocked. No bloods could be drawn from it but prehydration commenced hoping that it would flush itself in the process. It appeared that this did the trick as the following day a blood sample could be drawn off, albeit after a little perseverance by a very patient nurse. At 2.20pm on Tuesday 19th May, after a full 24 hours of hydration, the MTX infusion commenced. Frustratingly, his platelet, neutrophil, and white cell counts were just beginning to climb following the first course of chemotherapy. However, the principle behind the protocol was to deliberately time the MTX to strike the body's cells as they were beginning to recover. It appears you have to be cruel to be kind when fighting this type of tumour. After a good nights sleep Gareth woke at 8.00am to a soaking bed. One of the consequences of all those fluids going in is the urine volume increases also! I lost count as to how many bed changes we went through throughout his treatment! His low platelet count was indicated by his gums bleeding when he cleaned his teeth. Good old Gareth however, never to be downhearted, simply spat it out and then took great pleasure in telling everyone about it.

The following day we saw the neurosurgeon, Mr Flint. He was pleased with Gareth's recovery from

surgery and stressed that he was very willing to carry out further surgery if it was required in the future, but he was hoping that the chemotherapy would do the rest of the job for him. He took a great deal of time to explain the surgery he had carried out and he showed us the before and after images from the MRI scan. The difference between the two sets of plates was remarkable. It was wonderful to see the hard evidence of a scanned image clearly showing the success of his 'knife'. We thanked Mr. Flint once again for his work with our son and, as we left the room, he told Gareth to "look after mom and dad"!

Meanwhile, back on the ward bloods taken that morning were showing a sudden drop in haemoglobin level (Hb). Overnight it had fallen from 7.0 to 5.0. It was important to boost this in order for Gareth to be well enough and have the energy to keep up the fight against the MTX, so a transfusion of concentrated blood cells was organised for later that afternoon. It was now Thursday and, after an emotionally challenging day, Glen went home exhausted whilst I stayed with Gareth in hospital. It was important for Glen to try to be a normal mum to the girls for a few hours. Frustratingly, by 7.00pm his temperature spiked 38°C (the trigger temperature at which point a course of antibiotics became the automatic prescription.) To the normal child a spoon of Calpol would alleviate the situation, but to a child with a neutrophil count of less than 0.1 such an increase indicating possibly a simple infection could very quickly result in death. Not a risk any of us was prepared to take. By 8.30pm he had been prescribed a 5-day course of IV antibiotics. This caused a crash dive in my morale. A guaranteed bed for another 5 days is difficult to handle when your heart is set on getting home, especially when you know that the third course of chemotherapy is planned to take place in only 8 days time. During the night he was restless and woke up at

4.00am. That was it, he was up for the day now. I felt shattered and was looking forward to Glen and the girls visiting later that day. When I rang home at 9.00am I couldn't believe the conversation which followed. Sarah had been sick in the night and was suffering from diarrhoea. No way could she (or Glen come to that) visit Gareth, the risks of cross infection were just too high. The only consolation for me was the fact that it was a Friday and the five-bed room we were in had its four other occupants destined for home for the weekend. Gareth and I had the room to ourselves. The peace and quiet was a luxury to be enjoyed. We were on day 22 of the chemotherapy cycle. The protocol was scheduled to last 379 days! I feared as to whether I could cope physically and mentally throughout this course, not to mention Gareth's little body having to fight to repair itself after 28 cycles of chemotherapy in a constant stream with no allowances for real recovery in between. In the quiet of the night I felt cold, scared and alone.

The chemical attack on Gareth's body removed any interest in food for him. Trying to tempt him to eat or drink became one of the major challenges which was to last for the following twelve months. By 8.00am on Tuesday 26th May, six days after being given MTX, and after a good night's sleep he actually asked for something to eat. My pulse rate increased as we all frantically raced around trying to get a meal sorted before he lost his appetite. Seeing him eat that one sausage for breakfast provided an unimaginable uplift to us all, nursing staff included. There was a bit of the real Gareth starting to reappear from the dreaded toxic state. We were discharged that same afternoon. It was so good to get into the sunshine, free once more. That evening a close friend of ours, a nursing Sister, baby-sat whilst Glen and I went down to the local pub for a drink. This was the first time we had been out together for almost three months. Where had all that time gone? We didn't

stay out too long because we felt guilty as well as being totally exhausted, but it was a much appreciated change to routine. Gareth slept sound that night and he awoke at around 8.00 the next morning happily lying in his bed until we went through and fetched him to join us in our bed. The girls came through and all five of us ended up being squashed in our bed for cuddles. Another memorable happy moment. The eating came on in leaps and bounds with him reaching a gourmet level of Cornflakes, mashed potatoes, sponge pudding, fruit and custard and ice-cream! It was a case of making the most of it. On Monday 1st June, which also happened to be my birthday, we were back in hospital starting the third chemotherapy cycle. This time the drugs were Cyclophosphamide with a Vincristine push. This proved to be the 'sickly one', however, the antiemetic medication did its work and Gareth took it all in his stride. We were home the following day.

Thursday 4th June we had an appointment at Stafford District Hospital for Sarah. She had been complaining of headaches long before Gareth became ill, and had been waiting to see an eye specialist. Simple eye exercises were advised to correct a slight eye drift. Trying not to be overly concerned or appear paranoid since, in hindsight, Gareth's first indication of problems was a squint, we took the ophthalmologist's advice and she began to complain less and less with headaches. This continued to lie in the back of our minds despite a thorough eye examination showing nothing more serious than lazy eye muscles. Later the same evening I received a call from a work friend informing me that a colleague had committed suicide three days previously. My immediate reaction was sadness followed by anger at him for taking his own life when Gareth was fighting for every second of his. I went to the cremation service and found it a very difficult time. A number of my work friends were there whom I hadn't seen for weeks, since

Gareth's diagnosis in fact. I had little contact with them at the service, it was neither the time or place to discuss my problems. The service itself seemed quite impersonal and throughout I looked at the coffin thinking one day this could be Gareth. How on earth could I cope if such an event came to fruition. Immediately after the service I quietly left hoping no one would really be aware of my absence. I would not have been able to talk to them since I was too wound up in my own grief at the time.

After a week at home I felt Gareth was stable enough to allow me to attend my guitar class at the local college, a hobby course which I had enrolled on months earlier. Well, I should have known better I suppose because I arrived home after my class to the announcement that he had spiked a temperature of 38.1°C and so we were off to hospital and admitted by 11.00pm. To Gareth hospital was his second home. Whenever we arrived at 'The Children's' (frequently in middle of the night) he would recognise the corridor and say things like "here again" or "coming to see the nurses". He would always say "thank you" to the staff after they had connected him up to his IV pump (what he referred to as his 'robot'). He frequently left them with a tear in their eye because he was so placid and grateful to them, he knew they were there to "make me better" as he would say. He would often say "sorry" after crying or objecting to some invasive treatment, which all staff found very touching. It certainly was a humbling experience to witness such behaviour from a young child going through this turmoil.

Looking in my diary for Monday 15th June still makes me smile today. It reads "Phone ward 5 re admission today for start of chemotherapy cycle four". The laugh was we were already in finishing off the 5-day antibiotics course. So, out went the antibiotics and in went the pre-hydration followed by the Cisplatinium. During the following three days Gareth was so full of

life. At one stage I remember him gasping for breath because he was laughing so much. It felt so good to see him coping with this course of chemotherapy with so little apparent upset. Doctors' rounds at 8.30am showed Dr. Bruce Moreland as the caring professional we knew him to be. He was aware from previous conversations that it was Jeni and Sarah's school sports day today. He told us that it was important for us all to be there for the girls so he went out of his way to make sure Gareth was off his IV drugs and discharged in time for the event. We promptly left the hospital with an appointment in hand for Clinic the following Monday and raced off to the girls primary school. Jeni and Sarah were so pleased to see us. We did promise them that one of us would be there, but they were overjoyed to see Gareth there too. It made their day so special!

Monday 29th June quickly came around, Gareth was better than he had been in months. You almost felt like saying "he's okay now, lets leave him to get on with life as normal". However, thoughts like that were quickly put into perspective. Tumour, despite being very small, was still present as far as we knew, and we had no choice but to push on in the hope of eliminating it completely. So, today became round two of the chemotherapy cycle. One full rotation of drugs had been given and we were now to repeat the rotation with cycle one, Carboplatin and a Vincristine push. A CT scan had been booked for 10.20 am the following day. It would be good to see evidence that the first round of chemotherapy had been having some effect on tumour reduction. We looked forward to viewing the 'images' with great trepidation. We did not have to wait long. Five hours after the scan Bruce paid us a visit with the words "brilliant - we have to look hard at the images and can just make out two tiny 'zits' of tumour. Continue with chemotherapy and book in for Monday 13th July for next course". Wonderful, that would give us a whole

two weeks at home. This was one of our high points throughout his whole illness.

Wednesday 1st July 1992. I went back to work today. Gareth was now at home waiting for the effects of the chemotherapy to wear off. My concentration was not 100% but I 'was coping' okay with the rigours of teaching with both the mental and physical demands that called for. Leaving school at 4.00pm I headed home never sure of what to expect. It was always a relief to see Gareth looking okay. It was almost a week since he had eaten anything and he was drinking only small amounts. The chemotherapy made all food "taste nasty" as he would say. By the following Tuesday he began to try food again and we were so pleased when he ate a few chips and swilled them down with a beaker of juice. Glen's dad had come down from North Wales for an overnight stay so I took him down to the local club for a pint. When I got back Glen was pleased with Gareth because he had drunk lots more that evening. His fluid intake was on the up, and he was now sound asleep. That is, until 4.00 in the morning when his temperature began to soar. Not surprisingly to us by now we were admitted to Ward 5, arriving at the hospital at 4.30am. The one consolation of travelling into Birmingham at such an unearthly hour is that there is negligible traffic! I left Gareth with Glen at 5.30am, got home, crashed out for an hour, then woke the girls to get them sorted for school. Once they were off to school I headed for my school to start a busy days teaching. Gareth spent the next eight days in hospital on antibiotics, followed by the next course of MTX chemotherapy. He was allowed home on Thursday 16 July only to be readmitted on Friday 17th when his temperature climbed yet again. By now this was becoming a not-unusual pattern of events. It appeared that his white cell count simply could not counteract the constant attack of everyday bacteria and viruses. The frequency of these temperature rises began

to cause some concern. There was obviously an infection running somewhere within his body and it was important for the medical team to trace the cause. Numerous cultures were taken and, after a couple of days, it was discovered to be an infected central line. Antibiotics continued and a decision was reached to give Gareth a naso-gastric tube so that he could be 'fed' via this tube. He was losing weight rapidly and the concern was that he would not have the strength to keep up the fight against the chemotherapy schedule. He was very distressed having the tube inserted but quickly came round to accepting it and never attempted to pull it out. Yet again, he seemed to understand that it was there to help him get better. Problems also developed with mouth ulcers and bleeding gums (another unfortunate side effect of chemotherapy). It was important for him to continue his oral hygiene plan but not easy to enforce when his mouth was so sore and gums bled with every stroke of the toothbrush. Mouth swabs became a temporary solution as they were less aggressive than a toothbrush but the whole process remained very painful for Gareth. It was the 30th July before we were to go home again. Chemotherapy had been postponed one week to allow him time to get back to a degree of normality after all the antibiotics courses had been completed.

CHAPTER 6

The Long Haul

The chemotherapy cycle continued throughout the Summer of 1992. No holiday this year! It's amazing how quickly the Summer months passed. The chemotherapy protocol continued to occupy our every waking day, but Gareth always managed to bounce back. The next major problem to raise its head appeared on Wednesday 7th October. Gareth had been admitted four days previous with yet another temperature only this time they were having problems in bringing it under control. Eventually it appeared to be stabilising so I rang school at 2.00pm to say I would be in work the next morning. By 4.00pm the tables had turned completely. We were taken completely by surprise when we were told that Gareth had been placed on that evenings emergency theatre list. Laboratory results had shown the presence of the Candida fungus in his central line. He was taken down into the bowels of the hospital to have an echo cardiograph carried out. This clearly showed the presence of candida sitting in his central line leading directly into the heart. They were concerned that should a clump of candida break away and pass into his bloodstream it could cause a blockage of the arteries. With him being neutropaenic he was "sitting on a time bomb and the tube had to be removed now!". They dare not risk the infection getting fully established in his bloodstream. He was started on Amphoterasine antibiotics immediately.

At 6.00pm I rang Sue and John, two close friends and work colleagues, to ask them to pass on a message to my school saying that I would not now be in work the next day due to the new information we had received from the doctors. I'm sure Sue and John do not realise to this day how helpful it was for Glen and I just knowing that they were there at the end of a phone

willing to offer support and to pass on information, sometimes painful information, to staff at school. They both knew Gareth well and listening to me going on about events during his stays in hospital could not have been easy. I thank them wholeheartedly for staying there with us and not running away as many friends and neighbours did during this very difficult period in our lives.

It was time for Gareth to go to theatre. As Glen lifted him from his bed he disturbed, awoke and smiled. There was a little apprehension displayed in his face but he made no sounds. He seemed content and reassured simply by being in his mother's arms. On the way down to theatre he was as 'good as gold'. Gareth was in theatre at 1.15am having his central line removed. Yet again we were left waiting at his bedside but this time it was less than an hour before he was back. In fact by 2.00am he was back in his bed, on the ward, asleep. The operation he had just endured posed new problems for us all. The fact that he had no central line, meant he would have to go through the discomfort of having needles put into his arm again. Finding those tiny veins was never easy in the first place. It was now becoming near impossible. One minute our mood was buoyant in the knowledge that he was improving, the next we hit base again with him having to undergo surgery. The feelings of depression and exhaustion I felt at this point cannot be described. The comment in my diary for this day was simply "Always expect the unexpected!"

By Saturday 10th October, the ward was desperate for a bed so they gave Gareth a platelet transfusion plus antibiotics and evicted us! We had to be back in the hospital for six hours on Monday for an infusion of further Amphotericin antibiotics and again on Wednesday but at least it gave us some time at home. After the Wednesday antibiotic dose, a blood culture showed that the infection causing the temperature rise

was no longer a threat so we had the best news of the day, he no longer needed the antibiotics and we could go straight home. Little surprises like this really gave us all such a boost. Things did, occasionally, go our way!

We attended clinic the following Monday for day 172 since the start of chemotherapy. Dr. Bruce Morland was a little concerned with Gareth's blood counts. The constant onslaught of chemotherapy was beginning to take its toll on his self-regeneration system. He was not having sufficient time between chemotherapy courses for his body to recover before the next bombardment. This was the very fine line which the consultants had to draw between pushing ahead regardless, in the belief that if his normal cell count is being hit severely then so are the cancerous cells, and allowing him to have some quality of life whilst he's on treatment. It was decided to give him another week to recover and, in the meantime, Bruce was to contact the trial co-ordinators of the chemotherapy protocol and discuss the possibility of reducing future dosages. A further two weeks went by before they felt Gareth was 'fit' enough to take on the next course. This delay worked out quite nicely for us because it meant fewer needles whilst he was without a central line.

One full month went by before cultured bloods showed clear of the Candida fungal attack. It was only at this point they could consider installing a replacement central line. Finally he was booked in for the operation on Tuesday 10th November. He had the central line inserted and left theatre at 1.15pm. We were home again by 6.00pm. All appeared well until the Sunday when he spiked a temperature. At 2.30pm we were admitted to a room on Ward 1. The oncology ward (Ward 5) was full. It was here we realised just how different the wards were and how their approach to nursing patients differed so much. By this stage we were used to having a great deal of involvement in administering Gareth's medications,

etc. We were now being told we must let the nursing staff see to everything and under no circumstances could we give any medication to our son. We had had a huge degree of control taken away from us instantly. The staff appeared to have no concept of how important it was that we remained actively involved in his treatment. Knowing we were involved, trusted and doing something positive and supportive for Gareth helped to keep us sane. Comment in my diary for that day desperately reads "...hope to move very soon...". Eventually on Thursday, after a painfully long two days, a bed became available on Ward 5 and we thankfully moved upstairs for the remaining duration of the course of IV antibiotics.

The following Thursday I was due to attend an RSA Information Technology Examiners' Conference at the Grand Hotel in Birmingham. This provided us with the opportunity for Glen to have the Wednesday night at home and enjoy a rare mid-week break whilst I slept at the hospital Wednesday evening and set off for the conference once Glen had arrived at 9.30am on Thursday morning. Amazingly the logistics worked well. It was a very strange situation spending the day at a beautiful hotel, eating a wonderful buffet and chatting away to other professionals on a topic which could not have been further away from my mind. I drifted in and out of awareness of what was happening less than two miles up the road at the hospital. I kept wondering what these other conference guests would think if only they knew my situation, but it didn't seem right that I burden them with my personal worries. I listened intently and went through the expected process of involving myself in the days training. Some of the concerns being expressed at the conference were starting to irritate, and phrases like 'get real' and 'is that all you have to worry about' came very close to being expelled from my consciousness. However, I survived the day and left

promptly at 4.30pm to return to the hospital to give Gareth a hug. He always managed to get me to focus on life's priorities.

At 6.00pm that evening Glen was receiving some in initial practical training on how to administer IV antibiotics via his central line. This was important to us all in a number of ways. One, if she 'passed the test' once future infections had been brought under control by the hospital we would be allowed to finish the remaining IV antibiotics at home and, two, it strengthened our bond with the hospital staff because this reinforced the fact that we were accepted as a major part of 'the team'. We were all in this battle together and they appreciated just how important Gareth's home life was to him and his family.

The following day was day 203 of the chemotherapy protocol. Cisplatin was being infused and Gareth's counts were higher than they had been for a long time. These were relatively good days. After numerous controlled 'practices' on Gareth, under the watchful eye of the Senior Sister, Glen was deemed to be fully competent in administering IV antibiotics and capable of flushing Gareth's lumens on a daily basis. As a direct result of Glen's newly acquired skills Gareth was discharged the following Monday together with a supply of medical equipment which would enable Glen to safely 'nurse' his central line. I am very proud of the way Glen took this task on board. It made a big difference to Gareth since it meant he could spend more time at home with his sisters. Gareth's central line consisted of two flexible plastic tubes which entered his chest wall and ultimately fed into the main artery leading to the heart. Any drugs administered here were circulated around the body in seconds. The external tubes were clamped-off with a simple plastic clip. Each tube (lumen) had to be 'flushed' daily with saline in order to prevent it from blocking up. The whole process

must be carried out under strict sterile conditions in order to prevent accidental infection of the lines. Glen showed tremendous courage and dedication in this task. We were always conscious of the fact that if the process was not carried out carefully we risked pushing a blood clot directly into the heart, or providing a direct access route into his bloodstream for any type of infection, neither to be recommended! In fact, on one occasion at home, a local Health Visitor asked if she could stay to watch because she had never seen it done before and was not qualified to assist in any way. That brought the task into perspective. This was a major responsibility which Glen had taken onboard and carried out with great precision and dedication. To this day, she still sees it was a task that “any mum would have done”, I think she is wrong. Many mums wouldn't and didn't!

Monday December 7th 1992 was the next important date in our calendar. Gareth was to have a CT scan to review the effect, if any, the chemotherapy was having on the tumour cells. The results proved to be excellent, no tumour evident! The tumour was indeed being affected by the chemotherapy and it was decided to continue with the protocol because they knew this type of tumour was particularly aggressive and they dare not risk stopping chemotherapy now. The only “marking” on the brain scan was the scar tissue damage from surgery. Words cannot describe my feelings on hearing this news. I was elated that all the hard work of the medical team and, not to mention, the discomfort and pain which Gareth had simply taken onboard, was beginning to pay off. He was clearly showing signs of remission. We dare not become too optimistic at this stage. There was still a long way to go to completing the course of treatment, which in itself was potentially threatening his kidneys and other vital organs. However, we felt that for today's news we could not be more thankful. The staff at the hospital were very pleased for

us, whilst at the same time reminding us that life is still very uncertain and things can revert back as quickly as they appear to have improved.

By now we were quite resigned to the fact that progress would fluctuate and we tried to make the most of the high days on the understanding that there would undoubtedly be crashing low days at some time in the not too distant future. We had seen it many times with other families on the ward. The one thing you never got used to however was hearing of the death of one of the children you knew at the hospital. In many ways Gareth totalled more hospital stays in 16 months than most other children and, as a result, we got to know many families throughout that time. Several instances stick in my mind when I look back. One, a beautiful Asian girl of about 8 years suffering from Leukaemia. On admission to the hospital her mother spoke little English. Both she and the child were so afraid. Gareth frequently found himself in the bed next to her so Glen and this girl's mum found they spent a good deal of time with each other during the day. Whatever language you speak, whatever race you are from, when it comes to your child dying we are all the same; scared, wanting to take the place of your child, desperate to take away the pain from their little bodies and the fear from their eyes. The feeling of helplessness can, at times, be overwhelming. This little girl's mum would go home at lunchtime in order to tidy the house and return in the afternoon, frequently with a cooked Asian meal for Glen to microwave and eat later on. Friendship such as this in all its adversity can be a reward in itself, you see people for what they are and not who they are. This is one lesson I will keep with me for the rest of my life. After many months this girl was coming on leaps and bounds. We were shocked therefore on our next hospital stay to discover she had died suddenly and quite traumatically whilst at home. I can't describe the pain that triggers inside knowing the

heartache this family were going through. Life is so fragile and truly unfair.

Another girl around 7 years of age, again with aplastic anaemia was 'full of life' despite the gloomy outcome that was predicted for her specific disease. My final memory of her is her bursting into song for the whole ward to hear, singing along with her favourite 'Queen' tape "Who wants to live forever?" She died only days later. She was so happy and 'full of life' on that day that news of her untimely death seemed surreal.

There are happier memories, such as Gareth's relationship with a lovely girl, Amanda who was being treated for childhood leukaemia. She was about 14 years old. Gareth spotted her straight away when she was lying in the bed next to his and he made his introduction with the words "Hey girl ... what's your name?". Remember here, he was only three years old! He never actually called her by her name and for the rest of their friendship she became known as 'girl'. The following Christmas they exchanged little presents with each other and yet another bond was made between two children of completely different ages and abilities. We were thrilled to receive cards and messages from her and her parents as the years went by telling us how she is doing and that she "remembers Gareth with affection". She has now graduated with a degree from Oxford University! I wish her every success and happiness in the future.

As Gareth's eating had been severely effected by the drugs, we were given a feeding pump to allow him to receive liquid feed via his naso-gastric tube whilst he slept through the night. Once again we took control of this facet of his treatment. Future chemotherapy was delayed on two occasions, once again because of poor blood counts, but on Monday December 21st he was given his final dose before Christmas. We got home that day at 2.30pm and decided to go down the local club in order to watch the panto which was put on by a

travelling company. The first half an hour was wonderful, Gareth, Jeni and Sarah were all laughing at the scenes then, suddenly, and unexpectedly he began vomiting. We left the girls to watch the rest of the panto with their grandparents, and brought Gareth home to give him further antisickness medication. Glen later went back to the club to sit with the girls and I lay with him on the settee where he soon fell asleep in my arms. Those quiet moments of peace and restfulness are treasured memories. Despite what he was going through, there were times when he looked completely at peace.

We had a wonderful Christmas Day at home and on Tuesday December 29th our clinic appointment went smoothly. I recorded the following values as usual and out of interest compared them to 'average values' for a 'normal' child (in brackets) Weight 17.1 kg, Hb 9.1(10.5 - 15.0), White cell count 1.5 (5 - 10), Neutrophils 0.6 and Platelets 44 (150 - 400). As a guide we had come to expect a blood transfusion if Hb fell below 8.0, a platelet transfusion if platelet count fell below 10 and he was classified as neutropenic if his neutrophil count fell below 1.0. During my "studies" of the blood system I also noted that white cells in the blood have a half-life of only 6-8 hours, red cells a half-life of 120 days and platelets a half-life of 5-7 days. It is amazing what there is to learn when you have the incentive! We were elated at these recent blood results, he actually had some neutrophils! Maybe, just maybe, we would get into the New Year without resorting to hospitalisation due to infection.

New Years Day, 1993. A New Year should bring about new optimism. Well maybe! We had got through the Christmas and New Year period without infection. It was wonderful to be a family at this time of the year. The children exchanged presents on Christmas day as they had done in previous years. Three of them on our bed tearing open wrapping paper. It was difficult not

finding ones eyes moist simply at this sight. New Year itself was quiet. No wild partying, Gareth was too vulnerable to infection to mix socially. A quiet period together as a family was all the medicine any of us needed at this time. Time to recharge our batteries for the continuation of treatment which was scheduled to start again with the drug MTX on Monday January 4th 1993.

There was no hospital bed available until 1.00pm which effectively meant an extra day in hospital since it would be late evening before his chemo drugs would be ready to infuse. It was always frustrating knowing that you were hanging around, watching the minutes turn into hours, whilst drug preparations were taking place behind the scenes. A full blood count showed zero neutrophils and only 6 platelets. We were lucky to have made it over the holiday period without infection. Perhaps fate had allowed us to enjoy this one last Christmas together undisturbed! A platelet infusion was deemed necessary before they could commence MTX. Four units were infused but he developed a severe reaction to the transfusion, not uncommon apparently, after so many infusions the body begins to get a little annoyed at all these foreign blood products being forced into it. From now onwards any platelet transfusion must only be given after a pre-med so as to reduce the effects of a reaction. MTX infusion began at 1.00am on Tuesday. By Wednesday 6th his Hb was down to 5.8, critically low and despite having the 4 units of platelets only 24 hours earlier his platelet count was only 18. During the day 180mls of concentrated red blood cells were infused. The following day showed an increase in his Hb count to 8.6, not good but much improved on yesterday. However, platelets were now down to only 9 despite the transfusion he'd been given. A further 5 units of platelets were infused.

Thursday January 7th, held a change in routine. We were due to visit the hospital optician to check the effect, if any, chemotherapy and surgery may have had on his vision. So, we picked up Gareth, trailing his drip stand, and escaped off the ward to visit another part of the hospital. It was a welcome change to routine, although a little difficult waiting in the eye clinic watching 'normal' children coming in for an out-patient appointment and a routine vision check. We got many strange looks from parents who were obviously shocked at Gareth and all his trailing pipe-work and drip stand. Still, the news on the vision front was good. There were no obvious signs of problems with his eyesight and we were to be seen again in 3 months time.

Friday, blood results today showed a stunning platelet count of 98! We can't remember the last time he had a count so high. An Hb count of 10.8 and we were due to be discharged once "flushing" had finished. On a high! One hour later doctors informed us that the MTX levels still in his bloodstream were too high for him to go home, but it was hoped that with continuous saline flushing through his body the levels should drop to an acceptable level by tomorrow. On a low! As this particular round of chemotherapy smashes Hb level they also decided to give a further 170mls of red blood cells to prepare for the impact which the MTX was about to create. Oh, and whilst we were there they decided to insert a new nasogastric tube. We had been offered the chance to try and insert the wire guided tube ourselves but declined since it gave Gareth obvious discomfort being inserted we felt we could not justify the upset to him. The quicker it could be inserted the better for him. At last, on Saturday MTX levels were down and we arrived home at around 3.00pm.

CHAPTER 7

The fight Continues

Tuesday 12th January 1993, 256 days since his very first chemotherapy drug was infused. Those early days of chemotherapy seemed a very long time ago now and here we were still fighting, but nevertheless showing good progress despite all the setbacks we had had to contend with. Clinic appointments continued to be a bit like a drug addiction, something we never really wanted to do but we knew we had to in order to maintain the momentum of the treatment, ultimately finishing with a cure!. Besides, how many parents can say they knew the precise weight, height, white cell count, Hb count, neutrophil count, platelet count, etc of their child on almost any day of the year! Today was exceptional, a phenomenal Hb level of 12.1, weight 16.8kg, height 98cm.

On the Wednesday we discovered Sarah had a slight temperature so we gave her a dose of Calpol. Alarm bells began to ring for us when Gareth later refused to eat any breakfast. His temperature was normal but we kept a close eye on him anyway. Sure enough, by 1.00pm his temperature was climbing rapidly and we were on our way to his second home in Birmingham! His temperature remained high all through the night whilst having IV antibiotics administered but then eventually it started to come under control during the next forty-eight hours. He was allowed home on Saturday for Glen to give the remaining two days of IV antibiotic treatment. The willingness of the hospital staff to train and support Glen in this task really paid off for us at times like this. We had an extra couple of days at home which was wonderful for us as a family and the hospital had a 'vacated' bed that could be used for other children in need.

Clinic the following Tuesday resulted in a postponement of chemotherapy. His platelet count was 9! This was considered dangerously low at the best of times, but to administer a course of chemotherapy with this level was considered to be just too risky. Instead of Cyclophosphamide he was given 4 units of platelets. In actual fact chemotherapy was deferred for a further three weeks due to poor blood counts. Eventually it was Monday 8th February (day 283) when his chemotherapy started again with the sickly Cyclophosphamide. We knew this drug gave the most violent symptoms of vomiting for Gareth and all we could do was prepare for it and support him as much as possible. At around 3.00 in the morning he started to vomit. Unfortunately, on this occasion his naso-gastric tube was vomited up at the same time so this had to be removed and a replacement one inserted the following day. With increased dosage of the anti-sickness drug, Ondansetron, he quickly settled and the next day was playing as if nothing had happened. Home the following day.

Clinic on Tuesday 16th February. It was half-term holiday for schools so I took Gareth for this clinic appointment. Glen had done many of the previous visits whilst I was at work so it was the least I could do to give her some respite from these mind-numbing sessions. Dr Mann could not fault Gareth, he was playing merrily in reception and full of conversation when talking to her. We were dismayed later on that evening when he spiked a temperature of 38.6°C and once again by 7.00pm he was in a bed on Ward 3 having IV antibiotics together with a blood transfusion to boost his Hb count. Circumstances changed by the minute in this stage of his treatment rather than by the day or week as happens with a 'normal' child. With the temperature quickly under control he was allowed home on Thursday for Glen to do the honours of completing the IV antibiotics for a further three days. That took us up to the Sunday and he was

due in on the Monday for the Cisplatin dose of chemotherapy. However, on ringing the ward early on Monday we were informed that they didn't have a bed available so we could have an extra day off. At 6.30pm that same evening we received a phone call from Dr Mann requesting we attend clinic the following day for extra blood tests. They needed to check levels of creatinin and electrolytes before administering the Cisplatin dose.

The results of blood tests taken the following day highlighted a degree of concern over his kidneys. They were beginning to object to the variety of toxins they were being expected to filter and that we now had the real prospect of kidney failure to contend with if chemotherapy continued. A kidney function test showed lower levels of a specific chemical than they would like. So, the dosage of Cisplatin was reduced to 50% which meant one 24-hour infusion instead of a 48-hour infusion. Dr. Mann informed us that she thought it likely that it would be the last time he would be given the cisplatin dose due to the potential risk of permanent kidney damage. In one sense this was exciting to hear because it was the first sign of light at the end of the tunnel. The completion of one tiny aspect of his treatment. On the other hand it was scary because you were always wondering whether the absence of this specific drug would allow the cancer to take a hold over his precious body once more. Still we had to continue to take each day one at a time. One of the nursing staff arrived at 6.00pm with the chemotherapy infusion and, on setting it up, the bag split squirting the drug over her legs. She quickly clamped the bag and scurried off to wash her legs so as to prevent any toxins getting absorbed by her skin. It was at moments like this that the reality of the situation struck home. This clear bag of fluid which had the appearance of a litre of water was in fact a very dangerous and deadly cocktail of toxic

chemicals. We were not playing around here with trivial medication, we were deliberately inflicting fatal blows to Gareth's cell structure. The hospital pharmacist had to be called in from home in order to make up a fresh concoction of the deadly cocktail since each dose of chemotherapy has to be specifically calibrated and matched to the individual child taking into account many factors including the child's weight. Eventually, at around 10.00pm chemotherapy started. After a good night's sleep Gareth showed no signs of nausea and happily ate two bananas during the day. We were home Thursday morning as soon as the post hydration process was complete. Saturday was to show another small milestone. Gareth had his dose of phenytoin orally on a spoon! This drug is an anti-convulsant and was prescribed after the brain surgery he had undergone in the early stages of his treatment. It had been over two months since he had felt the willpower and courage to take this medicine orally and we had resorted to 'feeding' it to him down his nasogastric tube. It was a glorious winter's day outside. Snow lay on the ground and it was bitterly cold despite the sun pouring its energy directly onto the crisp white carpet which was covering the grass. Gareth was so excited at the prospect of throwing snowballs at his sisters!

Two weeks went by together with our standard weekly clinic. It was now 'Scan day' once more. Tuesday 16th March 1993 was also Budget Day. Whilst most people were worrying about the Chancellor's quest to increase the UK tax revenue we were on our way to the hospital for a 9.30am CT scan appointment. As instructed by the consultant we gave Gareth a dose of a mild sedative before setting off for the hospital and, upon arrival had the obligatory height, weight and blood checks at clinic. By now Gareth was asleep in my arms. I carried him down to the radiography department and lay him onto the scanning platform. He slept throughout the

scan as they took 4mm 'slices' through his brain. The scan was then repeated after injecting an enhancing dye into his bloodstream in order to get a clearer image of what was happening to the various cell structures in his brain. We left the radiography department and went back up to clinic to have the carboplatin and vincristine dose of chemotherapy. All was complete by 3.30pm and we went home after an emotionally taxing day to await the outcome of the scan. At 7.00 that evening Geraldine (the family oncology liaison nurse) phoned to say that the preliminary inspection of the scan images were fine. We breathed a sigh of relief and knew we could now fight another day. Gareth was exceptionally well, eating fine and playing madly with his sisters. But, by 11.00pm he was being violently sick and we only had oral anti-sickness medication, no good if you are constantly vomiting the tablets back up. The hospital offered for us to bring Gareth in or, they suggested, we could collect some IV anti-sickness medication from the doctor on the ward and administer it at home since Glen had been trained in this procedure. We didn't need telling twice. I drove to Birmingham at 2.30am on that Wednesday morning, did a quick turn around and got home around ten to four. Glen administered the dose and Gareth settled within minutes of him receiving it. One of the biggest breakthroughs in chemotherapy in recent years has been the ability to control its side-effects more effectively. Anti-sickness drugs have improved tremendously and, although very expensive, these drugs make the world of difference to chemotherapy patients. After Gareth had settled down to sleep I too went to bed. It was now five o'clock in the morning and I managed to grab two hours sleep before getting up to do my stint in the classroom. I well remember sitting in the staffroom listening to colleagues moaning how tired they were and me thinking 'tell me about it'. No criticism meant here but everyone's perspective on life, along with its trials

and tribulations, depends upon ones personal experiences collected as we all travel the path of life. Everything is of course relative and you don't appreciate just how little sleep the body can function on when the adrenaline is flowing. The trouble however, is that living on one's adrenaline at such a pace and over long duration has consequences that you must pay for later on.

Day 337. Saturday 3rd April 1993. We were due in hospital that afternoon at 3.00pm for a transfusion of platelets, but Gareth couldn't wait. I know it's sounding pretty boring by now but at 3.00 in the morning Glen went through to him in his bed and found his temperature soaring towards 39°C. We phoned and were instructed to bring him in immediately in order to begin a course of antibiotics. Later in the day he was given five units of platelets and a blood count showed the largest neutrophil count he had reached since the start of chemotherapy, a massive 1.2! This was good news. Since it is the neutrophils which are primarily the body's natural defence mechanism against infection, it was hoped that maybe he could manage to fight this attack himself. Ironically, it is usually the attack on the body that helps to stimulate the production of 'extra' neutrophils. Sure enough, his temperature fell as quickly as it spiked so the antibiotics were stopped and we were released that evening. Great, one of life's little bonuses. By Monday however, we began to pay for this bonus. Gareth started the day with a cough then his nose began running like a tap. By 3.00pm his temperature had risen to 38.6°C. The hospital advised calpol 4-hourly in the hope that this would be all the outside support his body would require, after all his blood counts were much improved on previous weeks so maybe he would be able to 'hold his own' throughout this infection. By 11.00pm his temperature was still high at 38.7°C but what was more worrying now was the fact that he had tiny blood

blisters forming over his body and inside his mouth. These 'petechiae' are small purple or red pin-head sized spots that occur in the skin and are due to localised haemorrhages from small blood vessels. This was bad news, and potentially very dangerous, since it indicated a low platelet count. This meant that his blood had reduced its clotting potential leaving him open to risk of internal bleeding. He needed a further platelet transfusion. We took him to the casualty department at The Children's and he was prescribed a further five units of platelets, triple antibiotics and a bed on Ward 5 until the Wednesday. After his discharge we continued administering IV antibiotics until the following Sunday. Over the course of the next few days it became apparent that his platelets for some reason were constantly getting annihilated. Within the past 24-hours his platelet count had dropped from 26 to 4. On Sunday 11th April he needed yet another 3 units of platelets transfusing.

Wednesday 14th April 1993, day 348. Today started as a routine clinic day. Hb count was better than expected at 9.3, platelets now 14, white cells 1.2 and neutrophils 0.1. We were called into Dr. Moreland's office and unexpectedly told that Gareth would not be given any more chemotherapy. It was felt that his little body had handled the chemotherapy protocol extremely well to date but that there was now the danger of over exerting his body's immune system and his ability to fight back after each dose was undoubtedly deteriorating. Enough was enough. The scan results were extremely pleasing and it was felt that to continue the full course just for the sake of it was not in Gareth's best interests. Chemotherapy would cease as of immediately and the hospital would keep a regular check on him in the weeks, months and years that, we all hoped, lay ahead for him. We went home elated with the news that chemotherapy was now history and we could start to build him up again and try to achieve some semblance of

normality in the Booker family for the first time in over a year. On the other hand, however, we were scared. Cancer has a nasty habit of luring you into a false sense of security, we were afraid to be excited and we continued to treat each day one at a time. Our primary focus now was to get his blood count up to levels that could be expected in a normal healthy child. This proved to be no easy task. He needed a further 5 units of platelets on the Friday, but Dr. Moreland remained confident that his levels would begin to climb soon by themselves. One week later his counts were indeed beginning to climb but at an incredibly slow pace. Progress was gradual but at least it was in the right direction. Gareth was very active at home and loved spending as much time with his sisters as possible, constantly teasing them. He would frequently be found singing and dancing with them both. In the mornings he would lie in his bed singing to himself until one of us got up and disconnected his feed pump. For the first time in months we could think more long term. The hospital had arranged for him to see a local doctor who had the responsibility for assessing the educational needs of sick children. We were gaining confidence slowly. His appointment on Tuesday 4th May became a real turning point in our optimism. The doctor assessing him chatted to Glen, myself and Gareth. Right on cue Gareth would respond to the specialist's questions with all the 'right' answers. A 'play' session with the doctor highlighted Gareth's high level of cognitive ability and good physical manipulative skills. He even demonstrated his great sense of humour which was acknowledged by the professional assessor. We left the surgery so proud of our son's achievements and thrilled with the reassuring comments from the doctor who said that, educationally, Gareth was ahead of his years and that the slight weakness in his fine sensory motor control, due to the brain surgery, would improve in the coming months. We

My Grumpy Thumb

were elated. This indeed was one of those high days. A day to remember.

CHAPTER 8

News We Didn't Want

By Wednesday 5th May Gareth was really on the up. Hb registered a fantastic 12.3 and platelets an amazing 118, all achieved by Gareth's own body's mechanism. These were the signs we had all been patiently waiting for. His body was beginning to recover from the year-long persecution placed upon it by the toxic cocktail of chemotherapy drugs. The ten days which followed were wonderful. Blood counts were good and Gareth's eating had returned to some semblance of normality. He was full of life and everyone commented on his seemingly abundance of energy.

Saturday 15th May. We had great plans for today. A colleague of mine had persuaded me to go dinghy sailing with him. It was the sailing club's open day and they were hoping to enrol new members. As a sport sailing had never really made any impact on me before but Dave had convinced me that it would not only be relaxing but also therapeutic. I was certain that it would be good to get away from it all for a couple of hours now that Gareth was showing very positive signs of improvement and that all chemotherapy had ceased. Glen was all in favour of me giving it a try so I made a commitment to sail with him from 2.00pm 'till 4.00pm on that Saturday. However, it proved not to be because when Gareth awoke that morning he was very subdued and certainly not his normal self. We became concerned at 9.30am when he vomited and then slept for two hours. At 12.00 he retched and then slept for a further hour. We contacted the hospital oncology staff for advice. It was suggested that we took him in for a check-up. We arrived in casualty at around 2.30pm and he was given a thorough check over. By this time however Gareth was back to his normal self. He was playing, singing and chatting away quite happily. Typically children can very

often make you feel guilty about taking up precious hospital time and resources when to the outside observer there appears to be nothing wrong with them. Fortunately however, the staff knew us well and they called for a doctor just to inspect Gareth's shunt. Feeling the shunt below the skin everything appeared to be okay but the doctor agreed to speak to 'his boss' and phone us at home in the morning to summarise the outcome of his discussions. We headed for home at 5.30pm and Gareth fell asleep as soon as we arrived. Plans that day for sailing had to be abandoned and so too had the thought of us all going to the folk club, as a family, that evening. Well, best made plans ... and all that!

True to his word the doctor phoned us on Sunday morning to see how Gareth was. He appeared to all intent and purposes to be fine. He was eating and playing so it was agreed to just keep an eye on him. We were told not to hesitate to ring the hospital or bring him in if we felt concerned. It was reassuring to know that the hospital support system was still there for us whenever we felt the need.

On Monday Gareth played well but did not eat much. My parents came to visit during the evening and Gareth was full of fun and excitement but by Tuesday (18th May 1993) Gareth had taken a turn for the worse. He was sick on waking and became drowsy in the afternoon. He improved at teatime but by 8.00pm he was sick and drowsy once more. We rang the hospital and took him to casualty as instructed. He was exhibiting all the typical symptoms of an intermittently blocked shunt. If the shunt blocks, pressure builds up in the brain causing vomiting and, ultimately, unconsciousness. The fact that Gareth had been fluctuating between hours of normal activity followed by hours of drowsiness certainly confirmed the likelihood of a shunt problem. It was agreed that he would require a simple corrective shunt operation and that he would be put on the theatre

list. However, just for 100% confirmation of their initial diagnosis they decided that they would scan him. A scan could indicate precisely where the shunt was blocked and determine what part of the shunt would need revising. At midnight I lay Gareth on the scanning bed. Glen and I stayed in the scanning room with him and he was the perfect patient, never moving. The first run through showed the ventricles of the brain were not enlarged. They repeated the scan with dye enhancement. I turned and looked at the doctor through the viewing glass and saw the expression on his face. There was no question about it, in my mind it was clear that his face showed an expression of utter shock. I knew it was bad news! He came through and invited us into the nurses office. Whilst walking towards the office one of the staff who knew us well told him that we knew things were serious and we wanted the true picture. Once in the office he told us that the enhanced run through had shown numerous metastases, too numerous to count! Heidi the SHO whom we had all got to know well joined us in the office. She had tears in her eyes as she hugged Glen. She was as shocked by the find as we were. Dr Mann had been informed and she was to see us first thing the next day. My immediate reaction was to want to take him home. I didn't want another second to be wasted in hospital. I felt that this was now our 'family time' and that we had to make the most of every minute with him from this moment onwards. However, it was late and they suggested we stay the night whilst they prepare some form of palliative care plan for him. So with a little reluctance we agreed to stay the night, they found Gareth a bed on Ward 6 and started him on IV Dexamethazone which is a steroid used to reduce swelling in the brain. Glen lay next to Gareth on his bed as he slept through the night and I sat in a chair next to the bed. We both quietly wept as he slept, conscious of the fact that it was now around 1.00am and other

children and mums were sleeping. Today was the day I had hoped would never come for us. Gareth had fought valiantly and we had come through so much during the past fifteen months. It didn't seem fair that after such a long battle the carpet on which we all walk on through life should be pulled out from underneath us so cruelly.

Later that morning the ward began to come alive and Dr Mann appeared and escorted us to an office so she could speak to us in private. Last night was not just a bad dream, Gareth had at least eight secondary tumours splattered about his brain and there was no questioning the fact that they were inoperable. This was the worst case scenario possible for us. There was no question of a 'miracle' cure. The medical team had done their utmost and Gareth had put up a tremendous fight but it was clear now that we had to come to terms with the fact that he was going to die! The primary aims now were to relieve the suffering which was likely in the near future by trying to reduce the swelling within the brain using steroids and, hopefully, to prolong the period of quality life. Eventually I found the strength to ask "how long have we got"? The answer shocked as it struck home. It was thought days or, at most, weeks! We appreciated the honesty of the doctors answers but they stunned the heart all the same. My son was about to die. That was official and there was no question about it. We had to come to terms with that fact and, what's more, we had to go home and explain it to his sisters. I would not wish the events of that day on my worst enemy. We have no qualms over the professionalism which Dr. Mann and her team showed throughout his treatment. They always had Gareth's best interests at heart and I thank them all for the perseverance and dedication they showed. Even when the odds were stacked against him they never stopped trying. It is for this reason I accepted totally the decisive comments that were made to us that morning. After our talk we went back to Gareth to find him

happily chatting away to one of the nurses, fortunately oblivious to the news we had just been given. We have to remain thankful that he was too young to appreciate the imminent death sentence which had just been declared. We stayed by his side playing his favourite games and reading stories to him. Every minute with him now was to be treasured, quality time.

Later that morning a friend and work colleague phoned the ward. She had got the message that Gareth had been admitted again and was enquiring after him. I took the call in the Sisters' office and I broke down. Sue was the first person I had to say the dreaded words to "Gareth is dying and there is nothing that could be done....". It was not until I had spoke those words out loud that the implications of them fully hit home. For the first time in all our battles I was exhausted and had to admit defeat. It felt as if I had stepped into a huge void between reality and virtuality. No, this was the real world. People were dying every day but, being human I had conned myself in believing it could never happen to one of my children. Sue continued to talk to me on the phone and I appreciated this. There was nothing she could say to avert destiny but she stayed with us. I would not like to have been on the other end of the phone line on that dreaded day. What can you say to a person who has just been told that their three-year old child is going to die in a matter of weeks or even days? How can you console the broken heart of a father about to lose his only son? You can't, all you can do is listen and offer to 'be there' as and when needed.

For many reasons it didn't feel right that we were taking up a bed on the ward so I was relieved when they agreed to discharge us. Pharmacy had sent up the necessary drugs to allow us to control the expected pain and Geraldine (the oncology liaison sister) would visit us at home later. I could not handle heavy goodbye's by nursing staff since this time they really were for good, so

we quickly said farewell and slipped into the busy street. From that day we made a decision that the girls would not be going to school for the immediate future. We were going to make up for the lost time we'd had to endure throughout treatment and make the most of whatever remaining time we had with Gareth. When we arrived home the girls were pleased to see Gareth if not albeit a little surprised; they had expected him to be in hospital for several days on yet another course of antibiotics. Gareth was tired as so we lay him down to have a sleep during which time we spoke to the girls and put them in the picture. We left them under no illusions that he had come home to die. We explained there was no further treatment possible and that despite him fighting very hard, the battle had been lost. His body was simply too tired to fight any longer. They took the news quietly, almost as if they had expected this day to arrive. With tears in their eyes they asked the same pertinent questions which we asked at the hospital.

CHAPTER 9

The Caring

The following Friday, 21st May, we spent the day on the Seven Valley Railway with a close friend and his wife and daughter. We had a wonderful day but it was a double-edged sword. It was wonderful seeing Gareth having fun but heartbreaking in the knowledge that his body was shortly going to succumb to the cancer. We were aware that every move we made would have to be stored in our memories for ever, because one day very soon, we would be calling upon those memories to see us through the catastrophic times ahead. Gareth thoroughly enjoyed the ride on the steam train followed by an ice-cream on the edge of the river Severn. On the way home in the car he became restless and kept repeating the words "I'm tired I'm tired". We got home and Gareth seemed pleased to get into his bed and sleep.

The next morning there was a stark difference in Gareth. I didn't like to think he could possibly be deteriorating so quickly, after all it had barely been three days since we were given the dreaded news. But, sure enough he was in much greater pain today and very restless. I felt angry with people who suddenly appeared offering all sorts of trips and treats for him. Why did they leave it until he was too ill to take them up on their offers? Why did they not believe us months earlier when we warned them his prognosis was not good? I felt they had come to clear their own consciences, to be able to say to themselves that they had 'done their bit'. It actually hurt so much more knowing that the offers were there now Gareth wasn't capable of enjoying them! By 7.00pm that Saturday evening Glen and our nursing friend Sarah drove to the Children's Hospital to collect a syringe driver, morphine and an antiemetic. They arrived back around 10.00pm. Moments later the local District

Nurse was at the door. This was the first time we had seen her and she asked if she could watch to see what Glen had to do with the syringe driver because she had never seen one connected to a central line before and, further more, she was not qualified to handle such. We had to later smile at the irony of it all.

The next morning Gareth awoke at 5.30 promptly followed by a large vomit. I took him downstairs and lay with him on the settee where he settled back to sleep. For only the second time throughout his illness I remember feeling scared. He was white around the nose and lips and purple in the face. His hands were blue and remained so until around 8.00am. He woke at 8.30 and gave Jeni and Sarah a lovely welcome when they came down from their bedroom. He livened up as the day progressed and a little of the 'normal' Gareth twinkled through on occasions but he needed frequent naps throughout the day in order to replenish his energy levels. My parents came over in the afternoon and one happy memory is watching my dad holding Gareth helping him play swing-ball in the garden. Gareth chuckled so much. The rest of the evening he spent playing with his farmhouse and garage on the lounge floor. It was nice to see the three children busily playing together. Glen administered his IV medication at 11.30pm and he crashed out in bed.

Monday 24th May he awoke at 6.00am complaining of a headache. We went downstairs and watched Walt Disney's "Peter Pan" video which he loved. He took his oral medicine happily which was quite a relief. The phenetoin was crucial to him now in trying to reduce the risk of fitting. He also drank a beaker full of orange juice, which was more than he had managed throughout the past few days. He was rubbing his eyes a lot however, which made us think that his vision was possibly starting to be affected. He also had very itchy skin and this was starting to frustrate him. We

contacted Geraldine to check the medication levels he was currently on. The following week continued pretty much along the same lines except for the increasing length of tiredness he would exhibit. We had increased the morphine dose slightly in order to compensate for the increased pain he suffered on occasions but, relatively speaking, he remained on a very low dose rate. He quickly deteriorated and by Monday 31st he was now very poorly. He became far more restless and agitated and, after consultation with the hospital, we stepped up his morphine dose. Glen spent the night lying next to him in his bed because he was moaning so much and so very unsettled.

June 1st 1993, my birthday! The only present I wanted and prayed for I knew I couldn't have. I had conceded that point days ago. At 6.30am Gareth became very weak, semi-delirious at times and then at others quite logical. He was struggling to form words. I could not believe the contrast to just a few days ago. He seemed to deteriorate on a rapidly sliding scale. It became obvious by now that he would die very soon. We pulled together forming an ever-closer knit family. This was to be our time, just the five of us. He was sick again at 7.30am but still no sign of fitting. We had been warned that during these later stages fitting was to be expected. We asked a number of deep probing questions of Geraldine during these latter days. We needed to be confident that he would not be suffering unduly as a result of us remaining at home. We did not want him to die in hospital but, at the same time, we did not want to make his pain and suffering worse unnecessarily. We were reassured by the fact that no more would be done in the hospital than we were doing at home. No one could answer the question that was begging. How would he die? We had to live with that uncertainty. By now Gareth's conscious state was very limited. He was able to respond with head and eye movements and, after a

tremendous drain on his energy levels, he would occasionally lift his arm. I remember him lying in Glen's arms when he suddenly reached up and, with tremendous conviction and determination, placed his arm around her neck. He may have lost the ability to communicate verbally but, despite being extremely tired, he still managed to show his love towards his mum. You could see the love in his eyes. Quite ironically it was Gareth who was a power of strength for us in those final days.

After receiving the prognosis from the last scan, we'd contacted Acorns Children's Hospice for help and support. We were at a loss as to who to talk to about our plight. We needed someone who would listen and help guide us towards making the right decisions for us as a family. Immediately after that call for help we received a visit from one of Acorns' home support workers, Phil Smith. We were so lucky to have met Phil when we did. He had the courage to talk to us openly about the events that were going to come about. Gareth was going to die. We accepted this point but had never really thought about what to do when that time actually came. Phil talked us through all the options available to us in terms of the practicalities, and legalities, of having a child die at home. It was after all our prime intention that Gareth would die in his home environment if at all possible. Phil faced head-on the fact that we had a little time to plan funeral arrangements. What music would we like ... which speakers - if any ... burial or cremation? This honest speaking helped us to cope with the reality of the situation. It was agonisingly painful but we felt a degree of comfort in the knowledge that there would be no last minute disappointments or regrets with the arrangements, and to this day I am proud of what we did for Gareth upon his death. It takes a strong person with commitment and love to be able to talk so openly with the families of dying children and I thank Phil for being there with us during the worst time of our lives. We now

had a new focus. We could not save Gareth's life. We had fought the battle continuously for sixteen months or more and had lost control over that situation. We were firm in our new commitment that we would have total control over what happened to him after his death! We set about carefully planning out the funeral arrangements. Who would conduct the service? We did not want a vicar who did not know Gareth and we didn't have much time for 'religion' anyway. The obvious choice for us was the hospital chaplain, Kate. She knew Gareth well and he loved the attention she gave him. I never became aware of her pushing her religious beliefs at us whilst we were on treatment and she became a friend to us throughout our hospitalisation. She came out to speak to us at home and agreed to conduct the service. My teenage niece Becky wrote a powerful poem simply titled "Gareth XXX" and we asked Kate if she would be happy to read it out as a part of the service. It would have been too much to expect Becky to stand up at the service to read it out herself. Kate agreed.

We had decided early on that cremation was to be our choice rather than burial. The next step was to consider the music that should be played in the crematorium chapel. With Gareth lying on my lap it was obvious we had to play songs from his favourite Disney movie "Pete's Dragon". Our first viewing of this was early on in his treatment in hospital and we all fell in love with it, so much so that we bought Gareth his own copy and I lost count the number of times he watched it. The story in a nutshell is about a friendly dragon that appeared when Pete, a young boy, was lonely and needed comfort and help in finding a family to look after him. After numerous adventures Pete finds someone to love and care for him and his dragon leaves to help some other needy child in the world. The sound track "I love you too" seemed so appropriate to us so I set about recording it onto a cassette tape. This was to be played

during the middle of the service. Another tape was made of his favourite nursery rhymes which we agreed would be played on entry and exit from the chapel. This had to include, of course, “Twinkle, Twinkle, Little Star”, since Geraldine had nicknamed him “Mr. Twinkle” in hospital. We began to have firm ideas about what we wanted and we decided early on that nobody was going to determine Gareth’s last few days on this earth but Glen, myself and his sisters Jeni and Sarah.

Later that afternoon I was sitting with him in the armchair. He was unconscious and breathing very slowly and deeply. I remember looking out on our back garden with the sun beaming down onto the grass and thinking very deeply about ‘life’. How much beauty there is around us, which we rarely notice. I was aware that his breathing had got deeper and croaky. Then all went quiet. The expected intake of new breath didn’t come. It must have been a good twenty seconds of silence when suddenly he breathed. It was not the right time for him to let go. I remain convinced that he still had a degree of control over when he would stop breathing. His sisters were not around. We had always said that, if at all possible, we would be together when he died. From that moment we knew time was not on our side now. We erected a campbed in our bedroom for Gareth to sleep on. Gareth would not be left alone at night. My biggest fear at bedtime was the thought of going to sleep and waking to find he had died in the night. During the next couple of nights Glen would lie with him until the early hours of the morning.

It was now Friday 4th June 1993. Gareth spent most of the day asleep either in Glen’s arms or mine. His syringe driver slowly infusing morphine to relieve the pain. The girls had gone to their friends over the road in order to have a taste of normality with school friends. Geraldine arrived to check on things at around 4.00pm confirming that, with her medical experience, Gareth did

not have too long left on this earth. She was going away for the weekend but offered to stay with us if we wanted. It was a nice thought but we really did want to be on our own. Shortly after she had left his breathing began to get rough once more and intermittent. We decided that I should go and fetch the girls so that we could all be together. We all sat together, Jeni and Sarah sitting on the settee next to Glen who was holding Gareth. It seemed so right that the mother who had brought Gareth into this world should be the person holding him when he left it. I was on the floor near Gareth's head. We spoke quietly to Gareth all touching him. It was still very important for us to be able to have the physical contact with him. To let him know in some way that we were with him. He was never left to feel he was on his own. I felt his feet and was surprised at how quickly they had cooled. I was amazed at the rate at which the heat loss moved up his legs to his torso. His body was shutting down! His breathing rate slowed and became noticeably laboured. This went on for several minutes and it felt like he did not want to leave us. I kissed him and whispered to him the words "it's okay Gareth we all love you it's okay to let go whenever you want, we will always be with you". A minute or so later, he exhaled that final rasping breath and then there was silence. This time he was not to find that extra supply of energy to breathe again. Gareth was dead. The time: 6.30pm. The day: Friday. The date: 4th June 1993. We all held onto each other and quietly wept acknowledging the son/brother we had now lost forever. How were we to cope with life from now onwards. Glen and I had lost our only son. Jeni and Sarah had lost their only brother.

CHAPTER 10

The Formalities

I phoned the local doctor's surgery asking him to come out and certify death. The doctor arrived at 7.00pm looked very briefly at Gareth, filled out a death certificate, expressed his sympathy and left. As I saw him out of the house he ran to his car and returned to hand me a leaflet about a Bereavement Care group. His departing words were "contact them if you need to talk". I could not believe he had handled the situation so badly. It felt just as if Gareth had had a temperature and that he had written out a prescription. We were left with our dead son and a death certificate!

A little later that evening I phoned my parents and told them the news that Gareth had died. They came over together with my sister and sat for a while not really knowing how to handle the situation. What can you say? Glen was sitting on the settee with Gareth in her arms and Jeni asked if she could hold him. It was very moving, and very natural, to see our eleven year old daughter holding her brother in her arms lovingly. This followed with Sarah holding him. Gareth was getting passed between the four of us with the utmost love and respect and it all seemed so right. I'm not too sure how others saw it. I'm sure the 'older generation' which were present felt a little uncomfortable. In their day as soon as a person died an undertaker was contacted and the body was taken away quickly. This was not going to happen with Gareth no matter how uncomfortable others found it. We were going to take our time and savour those precious hours after his death. We knew those memories would have to last us for the rest of our lives so they needed time to be absorbed. It was now around 9.30 in the evening and we desperately needed to be alone with Gareth. A physical family of five for the last time, although we knew we would always remain a spiritual

family of five! Our visitors left and we discussed our options with our two daughters. We explained to them that we were going to wash and dress Gareth ready for when we called the undertakers. They were given the option of helping if they wished or we told them that we could leave him for the undertakers to dress. We carried him upstairs and laid him on a towel on our bed. Jeni hesitated saying "I've never seen a dead body before". This was something we all had in common, but this was no ordinary body. This was Gareth our son, our daughters' brother. It was the body they had loved and cared for during the past three years. Jeni suddenly said, "can he wear his checked trousers?" Sarah jumped in with "and his favourite 'Thomas The Tank' socks?" They raced into his bedroom and searched out his "favourite" items of clothing. It was a very proud moment seeing their actions at that this excruciatingly painful period of their lives. Gareth would have been so proud of them in the knowledge that they had the courage and strength of character to be there for him right to the very end. We removed Gareth's pyjamas and bathed his body with warm soapy water. The girls helped pat his body dry with a towel. We dressed him in his yellow striped shirt and checked trousers and his Thomas socks. Sarah brushed his hair lovingly. When we had finished dressing him we carried him downstairs once more and sat with him on our laps.

Moment's later Jeni asked if she could read him a story. She leapt up and chose "Knock, Knock, Who is There?" from the bookcase. Jenny sat down and Glen placed his body in her arms. She sat and read the book out loud to him. Sarah also asked to read a story. Despite being only seven years old at the time she wanted to take an active part in this process. She picked "The Hungry Caterpillar" and "Andrew's Robin" from the bookcase and sat with him on her knee in the same way as Jeni had done. She too read the story out loud for us all to be a

part of. This was a very precious moment that will always be in my memory. Weeks later Jeni explained to us ... “ I had been thinking how I could make it special, because once he had died, I was afraid I might forget him. I wanted to do something that would always remind me of Gareth”. Sarah also later told us ... “I did not want him to die and I didn't think about him dying until it happened. His head was resting on my shoulder as I read him two of his favourite stories”. I cannot express how proud I am of the way they acted during that period of their lives. During such tragic circumstances, love, understanding and an acceptance of life and, ultimately death, shone through their every action.

It was around 11.00pm when we decided to call the undertakers. We had 'said our farewell' as a family and had decided that we did not want Gareth's body to stay overnight. We had made our memories, and time would not take those away from us. It was time to move a step further towards the physical parting. The hearse arrived at 11.35pm and I opened the door to two men in black. They came in and spoke to us reassuringly. After a few minutes they asked for permission to bring in the coffin from the hearse and they checked with us that the girls wanted to be present. When the coffin was brought in Jeni was pleasantly surprised. It was a light woodgrain finish with white satin lining. Since we had been in touch with the funeral director earlier in the week they too had had time to prepare for the moment Gareth died. The coffin was opened and placed on the floor in front of where we were sitting. There was no pressure or urgency in the faces of these men, we were encouraged to take as much time as we needed. After a few minutes, and some quiet words to Gareth, Glen lay him in the casket. His hands were placed on his chest and his favourite small soft-toy rabbit was tucked within his grasp. We all gave him a final kiss and we wiped away a gentle tear that had dripped and rested gently on his cheek. There was no

great sobbing or floods of tears as one might expect. Our hearts were tearing apart at the thought of his leaving but we were saying goodbye to his body and not his spirit. Gareth was, and always will be, in our hearts. The lid was placed on the coffin and, when we gave the go-ahead, it was lifted and placed with grace and respect into the back of the hearse. It was only moments and the car had disappeared from view. I closed the front door and realised that we had reached a new turning point in our lives. We had lost the battle for Gareth. He had died, and we now had to come to terms with the fact that he was not coming back. I simply did not know if we would be able to cope with what would be expected of us in the coming days, months or even years. We all sat huddled together on the settee and cried. We talked as much as we were able and decided the girls would sleep with us that night. I remember vividly in the early hours of that Saturday morning, being comforted by my daughter Jeni. She had her arms around me as I wept. She had grown up so quickly during the months of Gareth's illness!

It was very strange when dawn rose the next morning. It appeared to all intent and purpose just like any other Saturday. I don't know what I expected but it felt odd that the rest of the world carried on with the normal routine of life. How were we to survive the new life we'd had thrust upon us, the life without Gareth. It was not a life any of us wanted. Was it indeed to be a life or simply an existence? It seemed surreal, sitting eating breakfast that morning in the knowledge that Gareth was never to be with us again. I would never hear his laugh, his cry, his singing or his stories. I would never feel the tender touch, the loving squeeze of his arms around my neck, his grasp so tight that his teeth would grit together as he said the words "I love you". I would never arrive home from work to the welcoming arms of my little boy that wanted a kiss and a cuddle. All that was now gone, I felt numb.

There were so many thoughts rushing around my head I found it almost impossible to stay focused on the more mundane aspects of daily life. Life had taken on a very different perspective and I found the borders between reality and imagination were becoming very blurred. I could not function as normal. One minute I was at ease with life in the knowledge that at least Gareth was no longer in any pain, and the next minute I would be depressed at the prospect of never holding him again. I had to try and refocus my energies towards maintaining some form of family life for the rest of us. I could not care about the problems or feelings of other people. We had to be selfish and think only about ourselves at this point in time. Anything or anyone else would have to wait until I was ready to deal with them, however long that would take.

Glen and I had the practicalities of Gareth's death to sort out. The undertaker proved to be a great support to us here. He sorted out the crematorium arrangements and informed us of the available dates, etc. Fortunately, we did not have to undergo the added trauma of an autopsy due to the circumstances of Gareth's illness and treatment. We have known of families who, having gone through the tragedy of their child dying after a long battle against cancer, have then had to face an autopsy because the child's death occurred at home. I think that would have been the last straw towards losing one's sanity. After fighting this disease continuously for over 16 months we were all totally exhausted, physically and emotionally drained. The knowledge that Gareth's body was to be left in peace now was a blessing to us all.

We were soon notified that the cremation service would take place on Friday 11th June 1993. We immediately set about formalising plans for the service. This was going to be done our way. We refused outright to have a stranger extolling Gareth's virtues at the

memorial service and we had already sought the help of Rev. Kate Ricketts, the hospital chaplain. She frequently came to see Gareth during his many stays in hospital and she never once forced her religious beliefs onto us. I would like her to know just how much this meant to us at the time. I am not an overtly religious person but I do respect other people's rights to believe in God, whatever, whoever and wherever their God may be. Kate prayed for Gareth on many occasions and we gained comfort in the knowledge that she was thinking of him. Gareth was always pleased to see her on the ward and we were thrilled when she agreed to carry out the service for us. We knew whatever she said would come from her heart and would come as a result of her knowing Gareth.

Glen, Jeni, Sarah and myself agreed there would be no flowers except for a simple posy from us which would be placed on his coffin in the hearse. We did not want people's money wasted on the extravagance of floral exhibits. Instead we requested that donations be made which would then be passed on to the 'Imperial Cancer Research Campaign. The next thing to gather together was music to be played at the service. This was going to be a child's service and hence we sought out music which Gareth loved listening and singing along to. I spend a couple of days recording just what we wanted onto cassette tapes. I made one tape for the entrance to the crematorium, one for the middle of the service and one for the end.

During the week following Gareth's death we were told of the option to 'view' his body at the funeral directors. Jeni emphatically made her position clear. She wished to remember Gareth how he was when she helped dress him in those last few hours at home. Both Glen and I were of a similar mind to Jeni and more than happy to go along with her feelings. We too were happy to leave ourselves with the image we had acquired in those final days but Sarah desperately wanted to see him

one final time and I could fully understand her needs. She needed to see for herself once more that her little brother was dead and that nothing was going to bring him back to us. She was only seven years old at the time and we spoke to her on numerous occasions over the following couple of days in order to ascertain why she wanted to see his body again. She was so strong in her opinion that we felt it would be wrong for us to overrule her and not take her to see him. I phoned the undertakers and arranged a viewing specifically restricted to just the three of us. No other relatives would be there. Once again, this had to be our time. Both Glen and I would be at Sarah's side and Jeni would have the option of joining us if she changed her mind later in the week.

When the time came to view Gareth, Jeni stayed at home with her grandparents. On the way to the funeral directors I was somewhat apprehensive. I had no real idea what to expect, nor was I sure how Glen, Sarah or I would react on seeing his body again. We were greeted by a receptionist and guided to a small room where Gareth's coffin sat on trestles. The lid was off and standing in the corner of the room, the small brass coloured plaque read his name accurately. We were respectfully left alone with him. The little boy that lay before us was indeed Gareth but his drawn features and cold body was not the Gareth we knew. It was immediately apparent that the fun loving, happy, lively spirit of Gareth now only existed in our hearts and minds. I touched him and was surprised at how cold he was. I checked under his shirt to make sure his central line was still in place, as we did not want anything changing after we had prepared him at home. He had been left as requested. Sarah touched him too and commented how cold he was. This seeing and touching was an important part of her acceptance process. Tears slowly trickled down her face as the inevitable sank in. She realised now that he was never coming back. His

death was not an imagined nightmare but reality in its worst form. I took a photograph of Gareth that day just in case Jeni ever wanted to know more about our visit in the future. The photo remains safely stored but Jeni has never requested to see it, despite knowing of its existence. We all respect her judgement and feelings and admire her for the way she has maintained a degree of control over her own needs throughout this time. We returned home and collected Jeni from her grandparents. Questions were never asked of us that day by close family and never have been since. Sarah's curiosity had been resolved and she seemed more content after the visit.

Friday 11th June 1993 soon arrived. When the hearse carrying Gareth halted at the crematorium a cassette tape was switched on and it played a melody of children's nursery rhymes, including the important one "Twinkle, Twinkle, Little Star". The coffin was gently positioned at the alter and one of the pall-bearers wiped a tear from his face as he turned to walk away up the aisle, this simple action stays in my mind just like a freeze-framed image from a video camera. Later on in the service, when the curtain was drawn around his coffin, the tape played the theme song from Walt Disney's "Pete's Dragon" which includes the phrases "...there will come a day when we'll both be parted... I'll never disappear... I love you too..." The silence as the words and sentiments of that song gently echoed around the building was as sharp as a razor.

CHAPTER 11

The Aftermath

A few days after the funeral had taken place we, as a family unit, decided we would like some form of memorial to celebrate Gareth's life with the added criteria that it should be accessible to us all each and every day. It was during the early days of Gareth's relapse when we decided his body would be cremated after death. We briefly entertained the idea of a burial plot in a cemetery but with little hesitation decided this was not what we wanted. We would hold onto his ashes until we, as a family, felt the time was right to 'do something with them'. As for the form of 'memorial', Gareth loved animals and nature generally, so it seemed fitting that we should create a pond in our back garden. We felt that such a memorial would be personal to us all, accessible 24-hours a day and our private space. It would also give years of future happiness in watching it develop into our own little thriving natural habitat. Somewhere we could simply sit and think in those low days ahead, which we knew would come in abundance.

We soon set about churning up an area of turf and digging out the kidney-shape we had planned for the pond. We spent many hours reading and learning all about ponds and pond life. There is no doubt in my mind that I desperately needed such a challenge in order to channel my energies, anger and frustrations at this heart rendering period in my grief. At least for a few hours a day I was concentrating on a physical task, something positive would come out of the toil at the end of the day. This physical activity helped me avoid the emotional turmoil that was going on inside my head. How could I talk about my feelings and emotions when I didn't understand them myself? My motivation was simply generated out of respect for my son. We had spent the best part of 16 months fighting the cancer within Gareth

every single day and suddenly that fight had come to an end. We now felt redundant, our caring skills were no longer needed. The cancer had beaten us. Our conscious minds were still in automatic pilot mode. We found we now had time on our hands which we had not had for a year or more. Gareth's drip stand stood in his bedroom but it no longer needed sterilising and setting up. The syringe driver in his bedroom lay on its side but it was now silent, not needing the morphine topping up or dosage calculations made in order to adjust its settings. The need for our attention every minute of the day was now gone. Just like the medical equipment that remained in the house, we too now felt surplus to requirements. Gareth's two sisters had matured beyond all measure during his illness; the truth is they had no choice. They had become much more independent and, if anything, I think they resented our new found attention focusing on them. In their eyes their feelings had come second for so long during Gareth's treatment why should they change now.

I soon realised I needed the physical pain involved in excavating soil just like a junkie needs his 'fix'. The hard labour that left me with blisters and aching limbs helped me vent my consciousness of the fact that I had let Gareth die. I had not been able to save him. My main role in life as a father was to protect my wife and children and I had failed in that primary role.

Desperate times followed, the numbness I was experiencing within me was like no sensation I had ever experienced before. I could have been an automaton for all I was aware. I carried out everyday tasks and chores but found I had little recollection of doing them. Why was I bothering to do them anyway? What is 'it' all about? Why are we here on this planet? Is this life pre-defined for us from the day we are born? Many spiritual questions were to remain unanswered in the months and

years that lay ahead. Many still remain unanswered to this day.

The month of June slowly passed and it was coming towards the end of the school summer term. There remained just a couple of weeks to go before the school broke up for the long six-week summer holiday. I decided that if I was to get back into my old role of teacher and face my colleagues then now was as good a time as any to do it. I simply didn't know how I would react to the 'normality' of the routine of teaching after such traumatic events at home. Surely I could manage the final two weeks of teaching for this academic year. I drove to school with great trepidation not knowing how my colleagues or students were going to react to my presence. It had been several weeks since I had been in the staffroom. The last time I was there Gareth was 'in the clear' and everyone, including me, was happy to simply get on with as normal a life as possible. The situation now however was far from normal. On many occasions, not least on that drive into work, I turned the tables on my thinking. I often posed myself the question 'how would I feel if it were a colleague and not me who had lost a child? How would I react to greeting them for the first time since their child's death?' This helped me through the wide array of reactions I got from people. How could I blame people for avoiding a conversation with me, or totally avoiding any mention of Gareth's name? Had I not the experience of a child dying I would have acted the same in their place. I understand how people worry about upsetting bereaved parents. I also understand the fear they have of saying the 'wrong thing' but I also now know that *not* mentioning the child hurts and upsets parents much more since, by the sheer omission, it implies that the child was not important. How is it that as a society we are quite happy to offer sympathy to a friend who has been burgled, lost their house to a fire or perhaps had their pet cat run over and

die, yet when the ultimate horror occurs avoidance seems the answer of the day. A few colleagues had the strength to speak to me and offer their sympathies, this was much appreciated. One special person, Marge our laboratory technician, still enters Gareths birthday in her diary every year and without fail, asks if we are doing something special when this day arrives. However, the ultimate heartrending, but brave comment came not from an adult colleague but from one of my young pupils. It was at the end of one of my Physics lessons. It was the final lesson of the day, the bell had gone and the class of 15 and 16 year olds had been dismissed. One girl was deliberately slow at leaving, offering to put up the stools of students who had left promptly. Once the room was empty of her peers she approached me and simply said "I'm sorry Sir, but it does get easier". When I asked her to explain her comment she said "the pain of losing someone you love is so great but time does make it easier to bear". She then went on to tell me about her 'little brother' who several years earlier had died after being hit by a car. I was unsure now what to say, this was totally unexpected. I thanked her for her very kind and brave words and she quietly left to make her way home. As I was left alone the tears welled up in my eyes, not because she had upset me by reminding me of my loss, but because such emotive words had come from someone so young. She was a very young girl but she had experienced something which many adults had had the fortune to avoid all their lives. This girl had some real understanding of how I was feeling.

Well the days went by and these steadily turned into weeks. The Booker family continued on with some notion of life. The daily chores of 'normal' family life had to be contended with, shopping still had to be done as did washing, cleaning, etc. It was amazing how the mundane aspects of life became even more mundane! The school holidays were very quickly upon us and

close friends approached us with a renewed invitation to join them on a family holiday. The original offer was actually made soon after Gareth had been given the 'all clear' by the hospital consultant. We thought seriously about the repeated invite and decided all of us deserved a break. There was also the hope that it would provide the opportunity to re-fuel our drained emotions. It was to be our first time abroad. We began to plan our break to the South of France with friends Kevin and Sarah and their son Oliver. When the invite was originally made we really started to get excited at the prospect of a holiday with friends in the sun. This dream was quickly shattered of course once Gareth relapsed so unexpectedly. At that stage the last thing we could contemplate was a holiday! However, the offer was reinstated by our friends and after some discussion we decided to accept. It was acknowledged that we, as a family, needed and deserved, a holiday and concluded that Gareth would be in our hearts wherever we were, whether we were sitting at home or on a beach in France.

On the whole the holiday went well mainly thanks to the real support and understanding of our friends. They knew not to get too worried when arguments flared up within the family. They gave us the space and permission to grieve in the way we needed to. There were times throughout those two weeks when we all questioned our right to be 'sunning' ourselves and smiling when our son and brother was dead!

It was almost six months after Gareth's death when problems became apparent between Glen and myself. Looking back now it is obvious that we were functioning in a numbed, desensitised automatic manner. I went back to my teaching in September, the girls went back to school and Glen stayed at home, alone. We rapidly failed to function as a family unit but we blindly carried on regardless until in November, Glen asked me to leave. We had simply run out of the energy required

to endure the long-term conflict that was becoming apparent. Glen simply had lost all will to 'fight' for what we had. Her life-long role of mother had changed now her son was dead. I refused to leave although I did go walking alone for a couple of days in the Derbyshire Dales. This gave me a little time to think about the past, present and future. I remember distinctly the B&B where I stayed in Matlock. I spent hours writing my thoughts down on paper. In the background the current Meatloaf single "I Would Do Anything For Love" was playing over and over again on the jukebox in the bar downstairs. I decided there and then that I was not going to walk out on my family. I did not believe our life together was finished. We had struggled so hard during the last two years to maintain some semblance of family life and I was not going to be the one to walk away. I returned home and eventually sought an interview with a Relate counsellor. This was the start of a long uphill struggle for self-survival, because I could not expect our marriage to survive if I could not understand my own feelings and accept my own failings. After months of counselling Glen and I began to set an even keel once more, although it was very much a cautious venture for a year or more. Grieving does not go away overnight. A time scale cannot be placed on such a process since each person is an individual and therefore by definition every person will have very individual needs and desires. The thought of suicide did pass through ones mind but I was fortunate in being of the opinion that such an act would have been a gross insult to the memory of Gareth. My philosophy has always been that Gareth had fought so hard and for so long to hang on to every day he could get that for me to consider throwing my life away in such a selfish manner would be the ultimate insult to his memory. Glen and I slowly realised that our grieving was taking very different formats. Once this issue was accepted we could start to move forward, but we

desperately needed the support of this independent third party to guide us through our thoughts and feelings. Without this support I can confidently say that we would not have survived the year. The intermittent use of the anti-depressant drug Prozac also helped to focus the mind. Putting life and its events into perspective is impossible if you are in a depressive state of mind. Every statement and action appears critical and negative. In order to re-construct 'normal' life after a tragic event one has to have a good psychological foundation to build on. I found Prozac helped to provide that firm foundation by allowing me to make fair judgements on any comments that were made and gave me the confidence to acknowledge the good points in my own personality. In essence I needed to like myself. I found this very hard to accomplish. I had always taken criticism as a personal attack and as a result generally had a low self-esteem. I was of the opinion that this was better than being obnoxiously over-confident but now appreciate the importance of finding a balance between the two extremes. I am still working on that one! The time had come for me to accept the fact that life was a one-way street in the sense that there was no going backwards, the choice was forwards or stationary, and stationary was no permanent option really because friends and colleagues would simply move past you leaving you even more alone and isolated. Life had to move on but not before I had taken sufficient time to process all my pain and acknowledge my loss. The finality of death leaves you all alone with many memories which need time to fuse into place, time which cannot be measured with a clock or a calendar.

Life continued to have it's painful periods throughout the years which followed. Not because of grieving for Gareth, that still continues unabated, but because of the effect his death has had on us as a family. To this day we still continue to have times when we are

far too hypersensitive. The slightest criticism will seemingly be taken as a severe personal attack. The vaguest innuendo can all too easily be misinterpreted as a destructive criticism of the individual self. At low moments like this I am at a loss as to what to do to remedy the situation. At times actions seem to require more patience and energy that I can muster. In many ways it would be easier to let things fall apart. Jeni went through a period when she did her damndest to keep her emotional distance from her mother and I wondered just how much she 'blamed' her mum for Gareth's illness and ultimate death. After all it was her mum who pre diagnosis was at home looking after the children whilst I worked. For months after Gareth's diagnosis however Jeni and Sarah were 'dumped' on neighbours and relatives, holidays became impossible! From a child's perspective maybe Glen was the obvious person to blame because the children did not expect me to be there all hours of the day. In effect it was their mum who had left them in order that she could be with Gareth! Looking at the issue from all perspectives just emphasises the cauldron of emotions that are involved within the family unit when caring for a terminally ill child. This huge vat of emotions often creates an explosive mixture. All that is needed is an ignition source which could be a simple passing comment. At this stage Jeni was a very level-headed individual, but a teenager all the same and having the typical teenage bouts of storming off to her bedroom playing loud music rather than confronting an issue, the question of admitting that she might be in the wrong would never arise. As all mature adults know admitting your faults is never an easy task and even more difficult for a growing teenager. She would occasionally make comments that hurt but I knew this situation was really no different to any 'normal' family scenario with teenager children. With nerves, feelings and emotions still very raw and

exposed it was typically Glen who would take such comments as an attack on her as a person and label herself as a 'bad mother'. I'm sure all mothers undergo similar problems whereas dads tend to be the one the teenage daughter will be more positive towards. This can cause greater problems when dad is now seen to be disloyal to mum by seemingly condoning the teenagers' actions.

Fortunately these low periods were counteracted by the good periods when we managed to work successfully as a family unit, having fun shopping together, playing games and planning holidays. These bad days would continue to recur regardless of the time since the death of a child. The following comments are extracted from my diary dated October 17th 1999:

".....Wow, this is really an angry stage in my life. I'm angry at being angry! I feel I am set in self-destruct mode once more. I thought I was through all of this but it appears the cycle has come round again. Why is it when you least expect problems, they arise? This is the third weekend now that has been atrocious. I don't feel I can take another weekend like this. What is the point in life when you find yourself crawling through the detritus of depression day after day? We walked over the Chase this morning, the autumnal colours were beautiful but could I talk to Glen about the way I was feeling? Could I hell! Perhaps I need the pain. Perhaps I need to inflict pain on the ones around me I love dearly. Perhaps I'm cracking up? Perhaps my heart is tearing apart again at the thought of Gareth and the fact that it would be his 10th birthday next weekend. Next weekend should be real fun after the last three we've all endured....."

"...I recently read Shirley MacLaine's book "Out on a Limb" which I took very much to heart. She searched soul and mind to discover the meaning of life. She appears to have found it. I wish I could! I have lost any faith I had in life supposedly having some purpose or

meaning. It defies my logic but I desperately seek someone to convince me otherwise. Stick the religious aspect that talks about God and God's will. I have no time for such excuses that mask the pain which goes on in society today. I want to know the real purpose for our existence on this planet. Is there life after death? Is there such a phenomenon as re-incarnation? Do out of body experiences really occur?.....”

For the time being however we simply had to continue to strive to make the most of our lives as a family unit. Whatever the future may have had in store I gained peace in the knowledge that when we needed the strength to face the greatest challenge any family can be asked to face, somehow we found it. Gareth will remain in our hearts for all time. As a bereaved parent you realise just how vulnerable your children are and that, no matter how hard you try, you cannot protect them from the inherent dangers of being alive. Life is a risky business! However, I feel sure that our two remaining children know that they will always have us here to turn to in those difficult periods ahead, as well as the happy ones. I am so proud of the way in which both of my daughters have grown into caring young women who have a great deal to offer society in their years ahead. Today I realise we must all put our lives into the hands of fate. The only certainty for us is that a little piece of Gareth will remain in all our hearts for as long as we live. His character has had an effect on us as individuals and, as a result, we are all the better individuals for having had the fortune to have been a part of Gareth's life. Thank you Gareth.

Final Update

Our eldest daughter Jeni is now the proud mother of a beautiful baby daughter, Megan. She has temporarily halted her study in Psychology at University in order to

take on the wonderful mother role which seems to come so naturally to her. Sarah continues to work hard and is now studying for a Radiotherapy Degree at University of West of England, Bristol.

Sadly some aspects of my life have not gone in the direction I had hoped. Glen and I have divorced and we are both now trying to build new relationships. Hopefully the positive aspects of our long marriage will enable us both to develop firm foundations for a happy life once more. I sincerely wish her well. The family however continues to remain my reason for living and I enjoy the company of my children as much now as when they were younger and more dependent

I hope I can be forgiven for finishing with this personal message to Glen:

'Thank you for the years of togetherness and the time and love you have given to bringing up our children. All three of them are a great credit to us both.'

Chapter 12

In Memory of Gareth

What follows in this final chapter of my journey are the written thoughts from Glen, Jeni, Sair and myself. Though they are not ‘works of art’ in the linguistic sense they are certainly ‘works from the heart’ in the emotional sense. Expressing our feelings and emotions in writing became an important part of acknowledging the loss and sadness we all felt at various times in the aftermath of Gareth’s death. Individualistic though the articles are the similarity in the pain and consequential emotional turmoil felt by us all is clearly evident. I include them here in the hope that others who find themselves presently walking a painful route through life may gain encouragement to express their own feelings in whatever way they find appropriate whether it be poetry, song, art, etc. The fact that the emotion is expressed is more important than the medium used to express it.

The Journey

There were five of us in the boat, a small, modest but perfectly adequate craft which my husband and I had built together in our early days of knowing one another. We had begun our journey in unfamiliar waters and it had taken us a while to master working together as a team so that our efforts complemented each other and our movement through the water became relatively smooth and straight. We were in agreement over our direction and not in any particular hurry, happy to enjoy the sights along the way. The weather was fair and the waters calm for the most part. Occasionally little storms would brew up but usually my husband would take the helm firmly and steer us through without too much permanent damage being sustained. My husband was the obvious choice for the post of Captain. His father had been the Captain of my husband's previous boat and, as a male, it was expected that my husband would one day be Captain of a vessel of his own. I, on the other hand, had no particular ambition to be Captain and it came more naturally to me, because of my training, to assume the joint role of first mate and chief cook and bottle washer.

After the first few years we were joined by our eldest daughter. For a while it was difficult to always get the balance right in the boat and we tried various ways until we found the right place for her. Soon she was joined by her sister but this time we had anticipated the problem of balance and were able to sort it out much easier. Finally we made our crew complete with the addition of a son. We knew that one day our daughters would probably leave our craft to crew for someone else and we expected that our son would be Captain of his own boat.

And so we had journeyed through life. We were a self sufficient unit, we weathered storms without assistance and although various storms had caused us damage we were still afloat with all members of crew still on board. The crew had come close to mutiny on one or two occasions but the Captain had made a few concessions to his crew's needs and so the crew had remained in tact.

There had been no warning of the rapids up ahead. One moment we had been idly floating along, enjoying life on board and happy to go where the currents took us and the next moment we were fighting to regain control and steer a path through chartered waters. We were tossed about like a cork in the open sea. We donned life jackets and battened down the hatches. We wondered if our little craft would be strong enough to survive these rough waters as we had had no training for anything like this. We radioed for help and our calls were answered and we were given lots of helpful advice. However, we were alone in the boat and we clung on to each other, fearful of what might happen to us. It was vital that everyone pulled together and that we all understood our role as crew member. Try as we might there could be no turning back, all our attempts to turn our craft about had failed. We had slowed our journey through the rapids only slightly and now we were entering waters that were completely uncharted. There would be no lifeboats, only onlookers on the bank who had gathered there to witness our impending disaster. Oh, how I wished we had been more alert! Why hadn't we seen this coming? Perhaps there was something that we could have done to have altered our course if we had only realised sooner what was up ahead. There must have been some signs we missed.

As we rounded the bend, the speed of the water increased and we abandoned all futile attempts to control our course. We were powerless and could only wait

helplessly for whatever fate was in store for us. We feared for our lives and our little boat which had served us so well. Would the damage from previous storms have weakened its structure too much to survive this rough ride? All we could do was hold on tightly to each other and hope we would survive.

Suddenly, we were there. The roar of the water ceased and we were as if suspended in time on the very brink of the precipice. Below us white foam and in front of us just space. Even then I looked for something solid to make a grab at. But there was nothing.

And then we were falling. It seemed endless and in slow motion. After the turmoil of the rapids, the waterfall seemed almost calm and beautiful. I wanted to stay suspended there, forever in silence.

The shock of hitting the water took our breaths away and we were separated by the force of the water. I travelled down into icy depths where there was darkness and silence again. I felt numb and sleepy. I could have closed my eyes and let the waters take me then but somewhere in the distance I think I heard a cry and so I struggled back up towards the light at the surface. I was just about able to gasp one breath before the currents were dragging me under again. Once again I struggled upwards and this time caught sight of my daughters and husband. Again and again I struggled to the surface only to be pulled under once more. It seemed for a long time that the current would defeat me completely. It would have been so easy to give in. I was becoming increasingly weary and the struggle seemed endless. The distance between myself and what was left of my family seemed to increase the more I tried to reach them. I had no idea what had become of our boat or if we would ever be able to voyage in it again.

After what seemed an eternity I arrived, battered and bruised, on a sand-bank at the side of the whirlpool. I dragged myself out of the water a little at a time,

exhausted. Every inch of me ached, and I was cut and bruised from the many clashes I had had against the rocks. My husband and daughters had suffered very much the same injuries as they too had been swept around helplessly. They too were perched on ledges of sand at the side of the whirlpool. Our situation was precarious for at any moment any one of us could be swept away again into the torrents.

Our boat was a very sorry sight. Barely recognisable as the ship-shape little craft it had once been. The old areas of damage were once again gaping holes and new ones had been sustained in the whirlpool. We studied her and wondered if she would ever be seaworthy again. We did not have the tools to rebuild her nor did we have the energy to try.

For a time we lay on the sand-banks waiting for help but it was very difficult for any would be rescuers to reach us there. We were marooned on our own little islands, cut off from each other and the world. Alone with our thoughts and feelings. It became obvious that sooner or later we would have to risk going back into the water to try to reach higher ground where we could be reunited with each other and attempt the necessary repairs to our boat if that were to be possible. We knew re-entering the water would be perilous and painful.

One by one we tried to reach higher ground. We needed many attempts and sustained more scars along the way. We tried to give one another some words of encouragement but this was difficult as we each needed to find our own route to relative safety. Once there we found we could not just jump back in our boat and sail away as we did before. One of our hands was missing, we would have to redefine our roles. This was an unwelcome task. Also our boat was too damaged and needed much repair.

We encountered lots of people whilst we were on the high ground. Some looked on in silence, not

knowing how to help. Some were shocked by the damage we had sustained and were afraid to get too close in case they too became damaged. Some tried to offer words of encouragement. Some were happy to listen to our tale of how we had come to this place. Some had been to a similar place and were able to tell us their tales. Some people brought tools to help us mend our boat. My husband and I had been working on different sides of the boat with the children at the stern. We found we had been pushing the boat in opposite directions and had used up our energy working against each other rather than with each other. We needed someone who could direct operations, someone who had an overview of the situation and could see where each of us was working from. Someone who could liaise with us both as individuals and as a group.

It was not an easy task to direct operations. Not many people wanted that job. Luckily, we did find someone who was willing to try. His preferred method though was not so much to direct us but to help us direct each other. He also relayed instructions when they were unclear or misheard or when the distances between us were too great. He stayed with us until we told him it was safe for him to leave us. Even then he watched from the banks as we hesitantly re-launched our boat not knowing for certain that she would not sink. Gingerly we got back in, fearful that there might be a repetition of our ordeal or one very similar. We were aware now and ever watchful of the water. We knew it as our enemy as well as our friend and we no longer trusted it. We knew our boat could once again be swept away without warning. We knew that we could fall out and drown and so we watched each other. Several times we had to perform rescues as we were no longer sure footed on deck as we once had been. And so we moved away slowly hoping to reach calmer waters.

It is not easy as the whirlpool is never far behind us and its ripples go far beyond where we can see at present. We think they probably never disappear completely but we have found better ways to ride them than we had at first and we have learned to expect them. We have taken more tools with us on our voyage so we can do running repairs to our old and battered boat. As a crew we have learned to pull together and to look out for each other. Its harder work than it used to be and there are times when one or other of us really needs a break. We try to take the strain for each other but there are times when we could all do with stopping. We miss our youngest crew member in everything we do. You see he was in charge of the compass.

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I remember

I remember your steady heartbeat
As the gentle lapping sound
Of waves against a rock.
I remember your smile
Like the summer sun
Spreading warmth everywhere.
I remember your laughter
Like ripples on a pool.
I remember your tears
Like summer showers
Unable to dampen
Those golden hours.
I remember the calm before the storm.
I remember your love.

I remember your diagnosis
Like a giant tidal wave
Overpowering us all.
I remember my helplessness,
Drowning,
Feeling small.
I remember all the fighting,
Struggling not to drown.
I remember the franticness and urgency,
The need for everything done **now**.
There's no time to waste wallowing
When you're being swept along

I remember your relapse
When the waters began to subside;
For I knew then with certainty
That you would die.

I remember your last breath
When all hope went away.

The waters are still now
With icy blackness they remain.
With your death came
Hopelessness
And despair fathoms deep.
No point
In struggling anymore
Just silent tears to weep.
But inside me rages the greatest storm,
A tempest all of my own,

Forever looking for answers
Yet knowing there are none.
I remember you in the early hours
In the darkness before dawn.
I remember with everything I do
Behind false smiles I mourn.
I imagine all the might-have-beens
Of how you would have grown,
Your looks, your likes,
We'll never know -
But you would have done us proud.

I remember in your bedroom,
I pretend you're there asleep.
I remember creeping in at night
For one last peep.
But now your bed lies empty
Your teddies line the wall
Your clothes are folded neatly
Your books and slippers call.
My friends say time will help me-
It'll take away the pain.
But I don't want to forget - Oh no!
I want to remember -plain as plain.
I **need** to remember
For if I forget

How will I ever live?
I've already lost you once -
I don't intend to do it again.

I remember, Gareth.....
.....and I always will.

15/02/95

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It is vitally important to acknowledge the impact child death has on siblings. All too easily adults impose their 'grown up' beliefs on the remaining children thinking they are protecting them. It is very often the case that this 'protection' is actually encouraging deep seated insecurity and pain in the siblings. They need to be encouraged to talk openly about their brother/sister.



My Little Brother Gareth

Jeni Booker – (15 years old)

I can still hear him laughing
I can still see him by my side
I can still see his chubby legs
Running around my mind

I can still see “Tom & Jerry”
Hanging from his chest
I can still see all his little tops and
Little trousers and his little vests

I can still see his blue eyes
That sparkled when he laughed
I can still see him covered in bubbles
Everytime he bathed

I can still see him, hear him
And feel his gentle touch
I can still see my little brother
Who gave us all so much



The Reason He Had To Go

By Sarah Booker – (11 years old)

The 4th of June '93
That was when he went
They told me he was sleeping
But really I knew what that meant

But still I went on wishing
That he would come back
And we could carry on being a family
But missing out the days when he might never come back

I always saw his face
His blue eyes, his hair, his smile
And started running towards him
But it went on for mile after mile

But then I came back to our world
And started wondering 'Why'?
Why he was the one that had to go
And the one to leave and die

He was only three, coming up four
And now he will be eight
I can't help but thinking
Hate, hate, hate

But now I know why
Why he had to go
And I know that we will all have to go sometime
Whether we want to or not.

Winter Tears

It's been five very long years now since Gareth died and the longing for him never ceases to fade. There is not a day that goes by without my thoughts focusing on him in some way or other. My heart broke the day his body failed him and despite the many efforts at repairing it the damage will not heal. I image my heart to be shattered into many fragments only held together by the innate will to survive. At times of deep depression the pieces are bonded very weakly and could disintegrate at any second. At other times the bonds are powerful and all act in a coherent manner making the heart strong and my soul vibrant. The phrase heartache takes on its literal meaning during these long winter nights. I feel my heart physically hurting with the sadness. What triggers these feelings of depression I hear someone asking, the answer is simple, my son is dead.

As we pass through this life I like to think we carry with us a rucksack. In that sack we place all our experiences, memories, etc. My memories of Gareth always remain at the top of my rucksack so I constantly see reminders as I delve in to retrieve or store new items. I have positioned them deliberately at the top since they are very important to me. I feel society would rather me place Gareth's memories at the bottom of the sack in order that they rarely get disturbed. That way friends would not see my pain and they would not feel awkward or threatened. It distances them from the reality of life and reduces the likelihood of them having to resort to a phrase like:- "Time is a good healer", "things will get better", "you will get over it", "I know how you must feel", "you must think of something positive to take your mind off things" I know they are all spoken with good intention and are meant to make me feel 'better'. Unfortunately they don't help.

I acknowledge that I am sinking in my own grief, but I am comforted in the knowledge that I will float again if I am given time and space to continue to

My Grumpy Thumb

grieve in the manner which suits me personally. I need someone to watch me through this process without criticising or condemning. I need someone to be there ready for me when I once again feel able to talk. I need someone with a shoulder that will withstand the certain tears once they begin to roll forth. I need someone to hold me, protect me during my weakest days. I need someone!

I'm lucky, I have that someone close who carries out this role. I am safe in the knowledge that I can grieve at home and be guided through it. My heart goes out to those who are really alone and who's grieving takes place in complete isolation!

By Ken Booker - Written five years after Gareth's death

Just before I close this aspect of my life I would like to leave you with one or two points to ponder. There are many 'experts' out there in the field of bereavement counselling and during my journey I have read much in the way of research into bereavement issues which is to be applauded. I have also read much which has given me cause for concern about the way in which society tries to dictate the way in which one is 'expected' to grieve the loss of a loved one.

It should be remembered that grief is the very individualistic process of one human being interpreting their own inner feelings, fears and emotions in direct response to the loss of a loved one. No one knows how that person feels since no one can possibly have the same emotions, memories, experiences, etc. 'We' as individuals on this Earth should not fit neatly into boxes which describe the way we all react to grief. To compartmentalise grief simply belittles the experience of the individual and makes it more difficult for that person to accept the loss. I acknowledge the fact that there are some common behavioural responses to grief but the day we forget we are all individuals is the day we are not allowed to truly grieve.

The entire process of grieving is fluid. Movement backwards as well as forwards is to be expected and allowed for. The way ahead for the bereaved person is often unclear but it should be remembered that the purpose of grieving is to allow healing to take place. A time scale should not be expected or artificially imposed.

Gender differences can cause friction in family grief. One common frustration raised by bereaved mothers' is the apparent lack of grieving demonstrated by their husbands. The fact that 'he' is not crying is often interpreted as 'the male' not being affected as much by the loss thus implying that the mother is

undergoing a deeper grieving process which is a wholly incorrect interpretation.

Finally, I am now continuing my journey through life by 'living beyond' the loss of my child. I have not, nor ever will, 'get over' the death of my son but I can accept the loss in the knowledge that I am so lucky to have had the pleasure of Gareth as a part of my life albeit for only a short period of time.

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