

BackChat.....

Paediatric craniopharyngioma

When Daniel, my eldest son, was eventually diagnosed with a craniopharyngioma in December 1991, there was nothing to prepare us for the devastation that was to follow. My relief that at last there was a "reason/explanation/diagnosis" of what had been a long history of headaches, unexplained weight gain, poor growth, and several years of being labelled "an over anxious mother" while I watched my son suffer, was short-lived. I stood outside the children's hospital where he was eventually diagnosed, and looked across to the maternity hospital where he was born, and a feeling of *déjà vu* overwhelmed me. Only this time my whole world would crumble.

As Daniel had also been diagnosed with secondary hydrocephalus, he needed an operation to insert a shunt, in order to drain the excessive fluid from around his brain. As Daniel recovered from this first operation I had, for the first time, a glimpse of Daniel without the headaches and illness that had plagued him for so long and, for a short while, I believed that Daniel would "get better" and that his life would improve. We "celebrated Christmas" a little differently that year, and as we "prepared" for his craniotomy I continued to expect Daniel to make a "full recovery". Little did I know that this really was the beginning of a nightmare that would take away my son and give me back a monster.

There were three weeks between Daniel's eventual diagnosis and his first craniotomy. Three weeks where I had so little information, endless questions and no answers, and a real struggle to pronounce "craniopharyngioma" and to try and remember what the doctors and nursing staff had told me. Nothing to prepare me for the "Daniel" that I would be introduced to in the recovery room, the clinicalness of ITU and this very poorly boy, with a huge wound from just under his ear to the middle of his forehead, accompanied a few days later with black eyes, partial sight, very little short term memory, and a huge insatiable appetite. Then there were the daily blood tests where the nurses would hold Daniel down to be able to take blood from his groin and then later, his toes. All through this, I had no information, minimal support, and two very frightened young boys to "comfort".

As the weeks and months passed, and the bruises faded and the wounds healed, life got incredibly worse instead of better. My time was spent either

Many of the papers submitted to Backchat emphasise failures of communication. This month's is no exception, referring to the bewilderment of a parent starved of information about the likely consequences of her child's craniopharyngioma. In its guidance *Good Medical Practice*, the General Medical Council states that good communication includes "giving patients the information they ask for or need about their condition, its treatment and prognosis, in a way they can understand..." We know this does not always happen and the reasons are complex. How often has a paediatrician provided a long explanation about the strategy for treating a child's leukaemia only to learn months later that parents heard nothing after the dreaded word was mentioned. Explanations have to be repeated, often many times. Even recall in less fraught circumstances can be a minefield. In a response to the much criticised Griffiths report into research in North Staffordshire, two neonatologists pointed out that 18 months after a trial of clinical monitoring, 12% of parents could not recall having been asked for consent and 20% did not remember being given an information sheet, although consent was obtained and the written document provided by one researcher throughout. One answer, provided by Tracey Williams, is early referral to a patient support group. Every paediatrician in the UK should have a copy of *The Contact a Family Directory* on his desk. To get one, telephone 0207 608 8700.

attending outpatient appointments with Daniel, or trying to convince him that he wasn't hungry. At each and every outpatient appointment I believed that "this time ..." somebody would acknowledge that this was indeed a very different Daniel, that I wasn't heartless for refusing him food, and that the love/hate emotions that I felt the most, were shared by other parents and, most of all, were allowed.

Eventually, quite by accident, I came across a telephone listing for the Pituitary Foundation. At that stage I wasn't aware that Daniel's condition was pituitary related—despite the 100% hormone replacements he now needed. Through their literature, I was able to gain an insight into the role of the

pituitary gland and its importance, which was at least a beginning.

In the spring of 1993 I contacted my local Community Health Council for some advice. Even ignoring all of the heartbreak and hassles pre-diagnosis, I now had another battle on my hands. Daniel had returned to his school on a part-time basis, which was unsuccessful. My poor baby! Almost 13 years old and no life! He'd always enjoyed school and tried hard. He was missing his friends, his lessons, and a reason other than breakfast to get up in the morning.

In 1995 I met another parent, whose daughter, then aged 8, had just been diagnosed with a craniopharyngioma. The first time I'd met another parent! Yet, instead of being able to offer information, reassurance or support, all I could offer were copies of the Pituitary Foundation literature I had received.

In March 1996 I helped to set up and launch the Bristol Local Support Group. This was a very positive time for me, and as well as meeting up with other parents (rare breed that we are), I was able to learn about other organisations such as the Child Growth Foundation, and the excellent literature they produce, all relevant to paediatric craniopharyngioma.

For the first time since Daniel's diagnosis, I realised that I wasn't alone. The feelings of despair, frustration, and helplessness were shared by other parents.

By 1997 Daniel was very depressed, morbidly obese, extremely hyperphagic, and life for us as a family was unbearable. I secured a referral to the national centre for acquired brain injury at St Andrews Hospital, Northampton. How desperate must I have been at seven months pregnant. I informed the interviewing consultant that I wasn't leaving until he admitted Daniel!

For the past year Daniel has been almost self-sufficient, living in a self-contained flat. He has gained some coping strategies, attends sheltered employment daily, and attends night school, where he's learning computer skills. He has achieved his bronze Duke of Edinburgh Award and is working towards his Silver Award. What a proud mother I am!

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