

A Mother's Journey through Her Son's Anorexia

My husband and I have been married for 18 years and we have two beautiful children - a boy (15) and a girl (13) - we consider ourselves to be a pretty normal family. This is our story.

It was May 2004 when we realised our son's desire to be 'healthy' had gone beyond whatever normal is and that we needed help. He was a very sad young boy - aged 11 at the time. When we first visited our family GP it was mostly because he seemed a bit down, as well as his dieting. He broke down at the appointment, and then cried most of the way home as well; clearly something was wrong. I had thought someone just needed to explain to him that it was ok for him to eat sweet things sometimes - I never suspected an eating disorder - I didn't really know anything much about them. It was at a later appointment with a specialist pediatrician that the word 'anorexia' was first mentioned. It was quite a shock - didn't that happen to teenage girls? I was totally ignorant that it could happen to young children (or to males) and that it was a serious mental illness and not a lifestyle choice.

MALES

Yes, males can get eating disorders. The illness picks on certain personality types and when my information pack arrived from the EDFV I remember reading it and thinking oh yes, that's true, that's true, that's true. Many of the factors that can contribute to developing an eating disorder applied to our son – we just didn't know it.

- His self-esteem was low, he was not a very assertive person, he would put others needs before his own.
- He had been the easiest child to parent - in hindsight too easy.
- He was particular about collecting certain books/toys, sorting things, keeping his room tidy, etc.

He was showing some classic signs of an eating disorder:

- He had become increasingly interested in food preparation - but not necessarily the eating of it! And I thought he was being helpful by making his own lunch!
- He was exercising obsessively - running laps around the school, after running to school. A sudden interest in trying to do well in the school cross-country.
- His shower had turned into an aerobics workout.

He was not really obsessed with weighing himself but judged his appearance by looking in the mirror - how his tummy looked became his yardstick - and it was checked continually, especially before and after showering and toileting - I came to curse the lovely big mirror in the bathroom.

READING

I found reading all I could lay my hands on helpful and at times I couldn't get enough – I wanted answers. Back then I didn't have ready access to the web, but I found the local library and EDFV literature helpful. Reading stories of recovery and hope were encouraging as we began our

journey. Not everything we read was relevant to us (I found that a lot of information was about female sufferers) but I think the thoughts and feelings felt by the sufferers are similar as the illness doesn't know your gender or your age.

RECOVERY IS POSSIBLE

My hope is to reassure families that recovery **is** possible. It took some time to get to see the right people but it **did** happen. The doctor who eventually treated our son for his anorexia said to him at our first appointment that: "Yes, he was very sick now, but that he would get better, it may take 6 or 12 months but that he would get better". It was said with such calm conviction that I believed him. It was July and we were about to start our weekly outpatient visits; and these would continue until he was well enough not to need them. A life dictated to by appointments and a meal plan was about to begin.

Recovery is a different journey for everyone and everyone arrives at their own special place. This place will fluctuate over time. However, anywhere beyond the acute phase of the illness is a pretty good thing. I also acknowledge that there may always be some issues with food and body image for our son, and there will be some negative thoughts running around in his head but I believe his desire not to go back will help him to beat them. As was pointed out to me recently, it takes a strong person to deny themselves food, and it is that strength which can help a person fight the illness too.

TRIGGERS

Developing an eating disorder is not a choice, it does not have one simple cause, nor does it happen overnight. There is also no single factor or simple path to recovery. I believe there were many incidents and personality factors that contributed to our son's anorexia:

- He has obsessive tendencies, things that seemed quirky parts of his personality when younger, which actually meant that when he decided to cut certain foods from his diet - he was very good at it.
- He was worried about going into the upper school the following year and afraid of being one of the 'big' kids.
- He was having difficulty choosing which group of friends to play with at school and he hated the thought of hurting anyone's feelings.
- He was weighed and measured during a math's activity at school (a practice I would ban from schools if I could). A comment was made by another child about how much heavier our son was. Although their heights were also taken, our 10 year old did not understand the implications of him being significantly taller than the other child. Our son thought that his being heavier was a bad thing and he remembered this. He didn't mention any of this at the time and it was actually months later before he starting cutting out 'treats' from his diet.

We live in a society where we are bombarded with comments and images about the importance of our body's size/shape/weight. This information, combined with the factors in his life meant that our son had worked out what was wrong in his life and how he could make himself feel better - or so the illness had him believe.

GET HELP QUICKLY

I **strongly, strongly** believe that early intervention contributed significantly to our son's recovery. Being young meant that the majority of his eating was done in the family home, so when he became quite restrictive we were aware of it. However his thinking and behaviours had been changed long enough for the illnesses' claws to be well and truly in him before we reacted. We soon realised that we couldn't help him change on our own. Strangely, the fact that he was young helped our cause. I have always felt that because he was pre-pubescent this prompted the medical people we saw to monitor him very closely (there was a fear of him missing a growth spurt if he wasn't eating sufficiently). Consequently, he was hospitalised in the August, the **first** week his weight dropped. I encourage anyone who has suspicions about the normality or otherwise of a loved one's eating/exercise behaviours to seek help. It would be much better to be incorrect than to miss the opportunity of getting help quickly.

APPOINTMENTS

Due to our son's age, his counselor was the only person he saw on his own. He was always accompanied by us for his appointments with the pediatrician and dietician. We found that having two sets of ears at the appointments was helpful. When something new is being explained to you there is a lot to take in. Often it is easy to forget to ask all the questions you had too. We were lucky enough that my husband could arrange to be at all of our appointments during the acute phase of the illness. I feel this really helped our son to know that both his parents were very concerned about him. This also saved only one of us being 'blamed' for all the appointments he was attending. At times there was a very angry young passenger in the car.

HOSPITAL

I don't wish to dwell on the inpatient experience (which was three week's confined to bed with a naso-gastric feeding tube). I think it was certainly the lowest point of his life to date. That being the case, he had no desire to go back to hospital and in the early days this helped motivate him to stick to his meal plan. It was no picnic for us either.

I felt some pretty mixed emotions at the time. There were feelings of relief (guilty relief) that someone else was going to care for him. Relief that we would get a break from the two-hour meal sagas that had become the norm at our house. There were feelings of major inadequacy - that we couldn't make our son well and thus avoid him going to hospital. There were feelings of frustration at not being able to see him other than between the hours of 4pm and 8pm. There were often other visitors at this time and so there were sometimes feelings of jealousy. The grief of saying goodnight each day - occasionally the staff would have to peel him off us to let us go - it was awful. He was only 11 and wanted to be home with his family. We will never forget it. All that aside, the difficulties were worth it in the end as he, unusually, only had that one admission. I can't imagine what it must be like to go through multiple admissions.

DIETICIAN / MEAL PLAN

Living with a meal plan is quite a strange experience. It is the enemy of the sufferer and the crutch of the carers. The dietician we saw was just lovely and played a significant role in the

recovery process. She was someone we all trusted, believed and liked – especially our son – and I believe she was pivotal to his recovery.

WHAT WORKED FOR US

Our family was referred to a child and adolescent mental health service and after his admission to hospital we were assessed for ‘treatment’. We had no idea what to expect. Initially we imagined our son seeing ‘someone’ to help him with his thoughts and behaviours and that would be it. There was much more to it than that. The assessment process took time and his first appointment with his own counselor didn’t occur until October - these appointments then continued for the next 15 months.

I was surprised that my husband and I were offered our own counselor as well; however we found this an enormous help. The illness can present itself in many different ways during recovery and as the behaviours changed it was good to be able to talk these through with someone - there aren’t any magic answers and the sessions can be challenging but I would encourage anyone else to give it a go. You discover more about your own personality and behaviours along the way and learn that there may be things that can be done or said in a different way to help the sufferer.

We also accepted the offer of family sessions (these were monthly for a little while). These sessions were the most challenging aspect of the treatment for our family and there were days when the kids complained the whole way there in the car. The family sessions showed our son that we **all** wanted him to get better.

Another benefit was that the sessions validated our daughter’s role in the family and the fact that her life was turned upside down by this illness too. She will still mention being picked up from school each day and going to visit her brother for those three weeks - and that the three of us had to eat our dinner in the parents’ room each night. She was only nine at the time and I often wonder what effect the experience of her brother’s illness will have had on her now she is in her vulnerable teenage years. These sessions also highlighted that although one family member may have the illness - the whole family lives with an eating disorder.

SEPARATE ILLNESS AND SUFFERER

At its peak the illness takes over the sufferer’s life completely. The person you know and love will be buried deep below the strange behaviours you observe. We found it helpful to refer to the ‘evil voice’ causing him to do, think or say something. He even drew a picture of this voice - it was a fierce, nasty looking creature - no wonder he was scared of disobeying it! No matter how bad things seem - your loved one is still inside there somewhere.

LOVE

My early reading of recovery stories had a common thread - the sufferers were supported by the knowledge that they were loved unconditionally. During the illness we often told our son how much we loved him - and he would respond that he loved us. For a long time ‘I love you’ was still said daily to each other (it’s not so cool now when you’re 15!) however, I still remind him these days. We need to tell them that we love them because the illness would have them

believe otherwise.

LOOK AFTER YOURSELF

I was tempted to give up my part time work for a while (especially in the acute phase of the illness). In hindsight I'm glad I didn't, it meant that some part of my life remained 'normal'. (We were lucky that our son was able to continue going to school through most of his illness). I was also doing yoga classes for the first time that year and found it beneficial to continue those as well. They are still close to my favourite 90 minutes each week. I was aware of a TAFE college providing affordable student massages and I had these weekly for a while. You need your own nurturing while caring for someone with an eating disorder. Eating disorders become very demanding of your whole family - particularly when you are challenging it daily on behalf of your loved one – make sure you look after yourself.

MY JOURNAL

I found keeping a journal was useful. In the beginning it was mainly to record the advice given and appointments made. It became my close friend during the darkest stages of the illness. At the end of each day, when our son had finally succumbed to sleep (flat on his back because that way your tummy doesn't stick out) I would write about the day's events. I recorded the life our family was living and the strange behaviours of our son. I often couldn't make sense of what had happened and some days I couldn't quite believe the things the illness made him say and do. I stopped journaling after he had successfully started his secondary schooling and we had no more appointments – happily there was no longer a need.

ME NOW

I have been left with a number of legacies as a result of our son's illness.

I am extremely uncomfortable when hearing comments made about a person's body shape (either positive or negative), their weight gain or their weight loss. Telling someone they have lost weight is **not** a compliment. I just don't think we have the right to comment on a person's appearance - particularly as it has absolutely no bearing on what the person is like on the inside - and these comments may have far reaching consequences – you just don't know.

I cringe at what passes as entertainment on television and in other media and the effect this is having on the young people in our society. We hope our own teens are learning to question the validity of these shows/articles.

I am also frustrated with comments on food being 'bad' or 'good' or hearing 'I shouldn't eat this' or 'I shouldn't eat that'.

I have every confidence in writing a note to school when I don't feel comfortable with the content of the Health and Phys Ed homework – and have excused both our children at different times from completing certain tasks.

I still attend 'Support Group' meetings. There is a true camaraderie with other carers – we have all been there. I try to give hope that recovery is possible to carers who are in the midst of it all.

I'm still learning about the illness. Now as our son is showing an interest in trying to 'do really well' at school, I know to try and temper that desire in him, to try and help him to keep his life balanced and his expectations reasonable.

I have a desire to 'give back' and have spoken publicly on a couple of occasions of our family's experience. I am part of a group of carers who attend meetings with service providers who are trying to improve the care that is available to sufferers and their families. It is satisfying to be heard and to observe change being embraced.

I feel that helping our son fight his illness and to beat it, for him to be in recovery, has been our greatest achievement as parents. Never give up hope.