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Mark – a story of weight loss and Down syndrome – a mother's story

by Jill Harrison, Down Syndrome Association of Western Australia

Fifth July 2000, and I watch Mark running towards me holding the torch proudly above his head. The group of family and friends running beside him are clapping and cheering him on. Crowds line the road, but all I can see is my son Mark. That day of the Australian Olympic Torch Relay would be one of the proudest days of my life. It was not until looking at the photos later, that I realised how much weight he was carrying. No longer the cute chubby little boy. Now a young man, and an over weight 80 kilos.

Mark, my second son, has Down syndrome. After twenty one years I can still recall that moment when our doctor first said those words – Down syndrome - and how the world collapsed around me. We have come a long way since then.

But this is a story about Down syndrome, weight loss, and what is possible. It is about hope, commitment, sheer determination and will power. It is a story for all parents of a person with Down syndrome who is overweight.

All through Mark's life I had lived in the belief that one of the characteristics of Down syndrome, was being over weight, and that there was nothing I, or he, could do about this. So he grew from a chubby happy little boy, to an even chubbier teenager, and then into an overweight adult. But I didn't see what was happening.

It wasn't until I saw those photos of the Olympic Torch relay, that I realised how overweight he had become. And then something happened.

On the day before Mark's 19th birthday, at a routine Doctor's appointment, we were told that Mark was very overweight, and if we didn't do something about it, he would end up in hospital.

To say I was shocked is not quite the words to describe how I felt. I went through a process beginning with a feeling like being told all over again that Mark had Down syndrome, an absolute and heartbreaking pain. Then self-recrimination, self blame, and bad parent syndrome. Mark has the ability to sense how I am feeling, and so he felt my pain. That night was very unhappy in our household.

The next day I went to the supermarket feeling totally shattered. After spending about two hours scanning all the labels for any slight

information provided by
Down Syndrome Victoria
219 Napier Street
Fitzroy Victoria 3065
T: 1300 658 873
F: (03) 9486 9601
E: info@dsav.asn.au

www.downsyndromevictoria.org.au

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trace of fat, and comparing brand to brand, a friend past by. She asked me why I was looking at the fat content on the labels, and I broke into tears right there in the dairy section of the supermarket.

What followed from that day was an education process about diet, fat intake and exercise. A total life change for Mark and for us. A revelation for us and all who know Mark, as he shed 16 kilos over the next seven months.

I bought the fat counter book, the low fat recipe books, searched the internet for information, read the labels in the supermarket, and learnt all I could about fat. What is good fat and what is bad fat, what is the difference between saturated and mono-unsaturated fats? Which is better, olive oil or canola oil? Do you count fat grams or kilojoules? How to cook for a low fat diet.

But it was Mark himself who made the real difference.

Initially I thought the idea of Mark losing weight was, if not impossible, going to be a very difficult task. After all, he had Down syndrome, and aren't all people with Down syndrome overweight? Isn't that the image that people see of Down syndrome, the round face, the short and overweight physique? Added to that was Mark's love of fatty foods – chips, sausage rolls, hamburgers, fast food. Although we didn't have a lot of this at home, a night out was an excuse to overindulge, and I had recently discovered that he had been buying sausage rolls from the lunch van at work every day. How was I going to stop that? I couldn't be with him every minute of the day to monitor his intake. How was he ever going to have any independence from us?

What I didn't consider was Mark's own desire to lose weight. Mark has a trait of single-mindedness and stubbornness. For once, this would be Mark's ally. From that first day, Mark refused to eat fat. Before he ate any food he would ask, "Has this got fat in it?" Even when out and someone would offer him chips, he would say "No thank you, fat". He could recognise which foods had fat and which did not. And he would not be swayed.

In the past people had used food to reward, pacify, bribe or cajole Mark, or just to be nice. This had not done him any favours. He loved food, especially food with fat. However overnight he refused to eat it, and did not miss it. Possibly you or I would cheat and say, "I will just have one piece of chocolate, or one more chip", but not Mark.

He was an inspiration to everyone around him, as he went about losing one kilo a fortnight, until by early 2001, Mark had lost 16 kilograms. He went from 80 to 64kg.

However weight loss does not occur through diet alone. Sarah, from the South West Family Support agency in Bunbury suggested, and enrolled Mark at the Zenith Health and Fitness Club. Mark was put on a weight loss and fitness program that quickly reaped

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rewards. With two gym sessions a week, dragon boat training twice a week, and walks or a swim every other night, the weight fell from Mark's frame.

Mark was awarded the Gym Member of the Month Award in May of 2001, for his fantastic results. The citation in the Zenith newsletter read:

"Throughout his membership, Mark's desire to achieve has been a big part of his weight management. With a weight loss of over 16kg, Mark has amazed everyone with his endeavour to improve. Not only has Mark's results been impressive, his fitness levels have also increased in leaps and bounds. He is also over the moon with the development of a sporty physique. Whether it is dragon boat racing, row off competitions or interval training on the bike, Mark has remained focused on his goals showing that no barrier can hold back a desire to achieve".

To their credit, no mention of his Down syndrome. Mark was being treated and respected as would any other person.

Mark has been an avid dragon boat paddler with Bunbury crew, Forza, since 1997. Every Friday at training he would announce his new weight for the week. All the crew were extremely positive, encouraging and ecstatic about his results.

Since the initial 16 kilo weight loss, Mark has maintained his new weight for over twelve months. We are not so strict about an occasional lapse in his eating, but still stick to a low fat regime. What we have learned is that it is the fat in the diet that makes the difference. Not so much the sugar content, but often fat and sugar go together, like in cakes and desserts, something that Mark no longer eats. We eat only one or two meals of red meat per week, more fish and chicken. Lots of vegetables in low fat, quickly cooked, stir-fries. Pasta and rice. Low fat milk, yoghurt and cheese. Plain home popped popcorn cooked in the microwave without fat, instead of chips. Simply the healthy food pyramid diet along with an exercise program.

The results for Mark? A new muscly physique. Better health. Greater fitness and higher energy levels. Self-confidence. Pride in himself. New clothes! The knowledge that he can do anything he sets out to do. The admiration of everyone that knows him.

Mark is an absolute inspiration to anyone who wants to lose weight.

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Postscript by Jill (March 2009)

Down the track now Mark is continuing at the gym, and building on his muscles, but weight still remains a problem that must be constantly kept in check. It is far too easy to slip into bad habits. Mark has recently bought himself a rowing machine which he works out on days he is not at the gym and continues to dragon boat with the Forza club during the summer months.