

The Specific Carbohydrate Diet (SCD): Our experiences

By Sara, Tom's mum

The Specific Carbohydrate Diet (SCD) is not a new diet and has been used by mainstream doctors since as far back as the 1950s to treat coeliac disease and various other inflammatory bowel and gut conditions. It gradually fell out of use until rediscovered by the parent of a little girl who had severe ulcerative colitis. After her daughter had made a full recovery on this diet, the parent, Elaine Gottschall, went on to help many other people who suffered from serious bowel conditions. The autism community inevitably discovered her and there are now many stories of dramatic improvements in children with autism on the SCD.

I have only recently discovered the SCD myself but, in the short time that my little boy Tom, aged 5 ½, has been eating SCD foods we have been impressed with what we're seeing and excited about the potential of this diet. I am hoping to encourage parents to look at the SCD early on in the treatment of their child because I wish we had started a long time ago.

Why SCD?

It is always difficult to change the diet of a fussy eater but several things helped me make the decision to try out the SCD with Tom.

1. DAN! is reporting very positive feedback on the SCD from parents.
2. I had heard personally from several mums of children with ASD that they were seeing good results on this diet.
3. I realised that the SCD is for ANY and ALL of the bowel complaints that our children suffer (e.g. self-limited diet, diarrhoea, constipation, a distended abdomen, food intolerances, low appetite, over-eating, reflux, undigested food in stools, mucous in stools, pale stools, foul-smelling stools, fear of passing stools, flatulence, night waking and screaming, tummy-aches, yeast and bacterial overgrowths, etc.). Our children's conditions vary so much and it is great to find something that can potentially address all the varying gut problems that they suffer from. The diet works on the principle that, by giving our children only very easily-digested foods, we give the gut a chance to rest and heal.
4. This is not simply an elimination diet like the gluten-free and casein-free diet that Tom had been following previously. In Dr Campbell-McBride's book (see below for details) very clear guidelines are given on how to feed your child with beneficial and nutritious foods likely to help his or her gut heal and recover.
5. I was fairly sure that Tom would benefit from the SCD as he had always been a responder to dietary intervention. He improved dramatically when we removed casein from his diet. It was as though he had woken up and behavioural improvements continued when we removed gluten, soya, corn, yeast, rice and apples. He did very well indeed on Houston enzymes and he responded very negatively when we made the mistake of giving him shop-bought gf/cf food laden with yeast, sugars and additives.

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6. Although we had seen improvements, Tom's bowel problems persisted. His abdomen continued to be very distended despite various yeast and bacterial treatments, Oxypowder clear outs, umpteen supplements and probiotics. His diarrhoea didn't clear up and his sleep and eating habits were terrible – all evidence that we hadn't got the diet right yet! (We still use Oxypowder, enzymes and VSL3 probiotics, by the way.)
7. Following a diagnosis of reflux from Dr Fell of the Chelsea and Westminster Hospital in London, I was concerned that other parts of Tom's gut might also be inflamed. Tom had not improved on any anti-inflammatory herbal treatments, nor had the reflux drugs helped.

How does the SCD work?

The SCD is a complex diet so I have given an extremely abridged version of how it works in the hope that this will encourage further reading. Difficult to digest foods are eliminated from the diet. All carbohydrates are made up of molecules called monosaccharides such as glucose, fructose and galactose. Monosaccharides are the smallest carbohydrate molecules and are, therefore, easily absorbed through the gut lining—they do not require digestion. Monosaccharides are found in fruit, some vegetables, yoghurt and honey.

The next size carbohydrate is a disaccharide. Disaccharides require digestion and, in children with ASD, can cause mayhem by remaining undigested in the gut where they become food for pathogens. Undigested, they are ultimately converted into toxins which further damage the gut and poison the child's entire body. As a result, all grains and some root vegetables are eliminated from the diet until the child's gut fully recovers. Similarly, proteins can be divided into more or less complex entities. Casein and gluten are just two examples of those that are difficult to break down and digest. Eggs and meat, on the other hand, are very easily digested and are an important part of this diet.

Healthy and gut-healing foods are added to the diet. Fermented foods such as yoghurt (not the shop-bought variety) and sauerkraut are easily digested, provide good nutrition and good bacteria and, as a result, can dramatically improve gut health. Juicing fruit and vegetables (shop-bought juices are not recommended) makes them extremely easy to digest and means that fussy-eaters get a whole range of fruit and vegetables in a very easily digested and highly nutritious form. Meat and organ meats (sometimes contrary to current beliefs and habits) are very nutritious and easily digested.

Nuts, ground nuts, and nut butters form are simple proteins and are really handy for recipes and for making this diet more versatile and interesting. They can be used to make breads, cakes, crackers, pancakes and lots more, once the child is ready. (However, a word of warning: nuts contain lectins which can cause problems, especially for guts that are already damaged. Soaking nuts overnight helps to break down the lectins. Nuts can then be dried in an oven or under a grill or in a dehydrator before you grind them into flour).

Bone broths are simple to make in a slow cooker and provide a cheap, natural, and nutritious base for stews and other recipes. Healthy fats are very important for brain health and overall well-being in children. Fats such as organic virgin coconut oil or goose fat are best for cooking whereas olive and nut oils are best poured raw onto salads or other foods. There is a very good discussion on which fats are good for your child in Dr Campbell-McBride's book.

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Improvements we have seen

At this stage we have not managed to implement the introductory diet. Tom eats a lot and I am giving him loads of snacks which should only really be included later on. However, I am planning to get around this by picking two days when we will be at home and giving him lots of little meals throughout the day. Despite not doing the introductory part of the diet, we have seen lots of improvements and are hopeful of more when we do the diet properly. Tom actually likes the recipes in Dr Campbell-McBride's book and, for the first time, he is feeding himself. In the past I had to spoon-feed him most of his meals with the television on as a distractor. It is such a pleasure to see him tucking into the food I've made. It may even be the case that this diet has cleared up his reflux or healed his gut to the extent that eating is no longer painful for him. (For those children that do not like her recipes, the Pecanbread and other websites mentioned below offer very different and varied recipes and, hopefully, there is something for everyone.)

Tom is eating a greater variety of food than before. Despite the difficulty of changing the diet of a fussy-eater and cutting out more foods, I have actually increased his repertoire. Tom's abdomen is now much flatter. His sleep has improved. He no longer wakes up at night. (He does take Melatonin but that wasn't enough before SCD.) His stools are usually formed and more normal in colour. (Previously most stools were liquid). He complains less of stomach pain. He has shown a slightly increased interest in food – a first for us. He has been watching us eat and naming our food. He has asked me for milk three times and for an orange. I think he was previously afraid of all food, and I think this was indicative of the pain that eating caused him. His accidents have stopped completely and he is now properly toilet trained (this used to come and go.). He looks much healthier – his eyes no longer appear glazed and his pastey look and panda eyes have gone. Most importantly of all, he is a much happier much healthier little boy and, as a result, is keener to communicate with us and this is having positive knock-on effect on his development.

Practicalities

SCD involves an awful lot of cooking and it took me some time to get organised enough to do it properly. It helps if the whole family can be on the SCD but we are still working on that one because Tom and I have very different tastes! I am new to this and may well find better and cheaper places to source ingredients in the future but for now: I buy organic ground almonds from Sainsbury's or buy the organic almonds to grind myself from www.dietaryneedsdirect.co.uk who also sell nut butters and many other useful ingredients for the SCD. I order a box delivery of organic fruit and vegetables every week from a local supplier. We get through a lot of fruit and veg because of the juicing and I am looking for someone who can deliver another box half way through the week. I find that the fruit and veg delivered in the box schemes is much better quality and cheaper than the supermarket versions. I regularly order organic meat from www.wellhungmeat.com. This is top-notch, delicious but expensive meat so I also buy organic meat from the supermarket because we get through an awful lot of it. I actually bought a large second-hand freezer to help me to cut down on the amount of cooking I do and this has made life considerably easier. Tom has three cooked meals a day but now I always have at least two of them in the freezer. I get organic, extra-virgin coconut oil from www.virgincoconutoil.co.uk and will soon be trying to make my own goose fat. I have bought a Lakeland yoghurt maker and will be buying raw goat's milk from www.red23.co.uk who also sell sauerkraut (I will be trying to make this myself soon) and Herbamare which makes savoury SCD food taste yummy.

Further information

My own favourite resource is the book Gut and Psychology Syndrome by Dr. Natasha Campbell McBride MD, M.MedSci (Neurology), M.MedSci (Nutrition) because, I love the detailed advice she offers on food and nutrition. I like being told what I should be feeding my child and not just what I should not be feeding him. I also find it slightly easier that the book has a UK cultural bias. The American resources on SCD are all excellent too but I find it much easier to read about the diet when the cultural barrier is lifted.

Some other great resources include:

Breaking the Vicious Cycle by Elaine Gottschall

www.pecanbread.com

www.breakingtheviciouscycle.info

<http://www.scduk.co.uk/recipes.htm>

Treating Autism