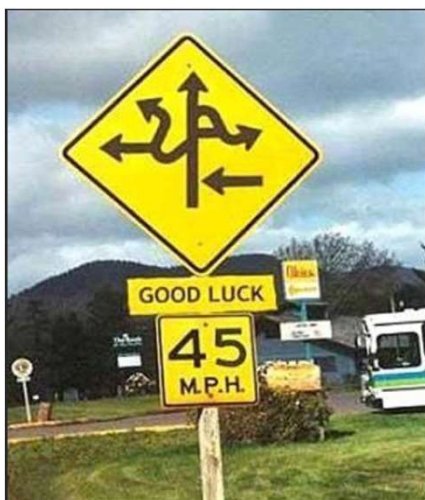




Overwhelmed



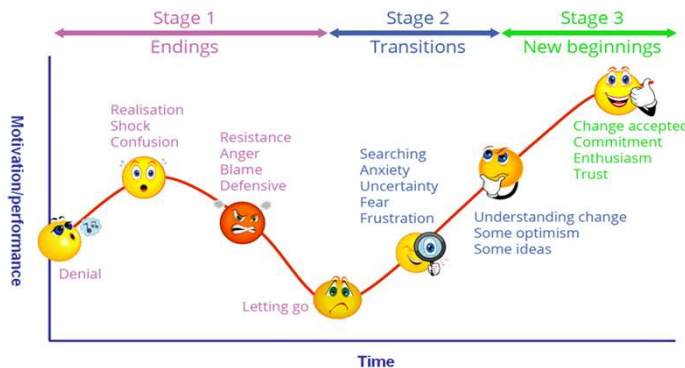
- What sources should we use as a guideline?
- The problem used to be lack of information, but now the problem is information overload.
- We are dairy-free, nut-free, egg-free, low FODMAP, no nightshades, vegetarian, keto....etc. Can we still make the diet work?

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This sign says it all. EVERYONE feels overwhelmed and confused when they start the diet. When we started 10 years ago – there was not enough information but today there is so much information- it's hard to know what to follow, so it is important to direct people to reliable resources.

With regards to the last question: YES. We have many kids with food allergies who thrive on SCD style diets.

Steep Learning Curve



• Progress is not linear

"defeat, disappointment, frustration, confusion and many other emotions come up with this process, but it is all worth it to gain even a little control over my child's wellness" (SCD mom)

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This is how progress looks like. It is not linear. The first year is the hardest. There are mistake and mini-flares that are built-in to this journey. When a mini-flare accrues parents go back to basic safe foods for a few days (soft cooked veggies and fruits, good fats, sometime removing dairy helps... in many cases a few days of safe basic diet help and we return to normal SCD... It's important to inform the doctor and to monitor with labs in these cases.

It helps parents to know that a bumpy road is part of the journey, it does NOT necessarily mean that the diet is not working.

Deprivation

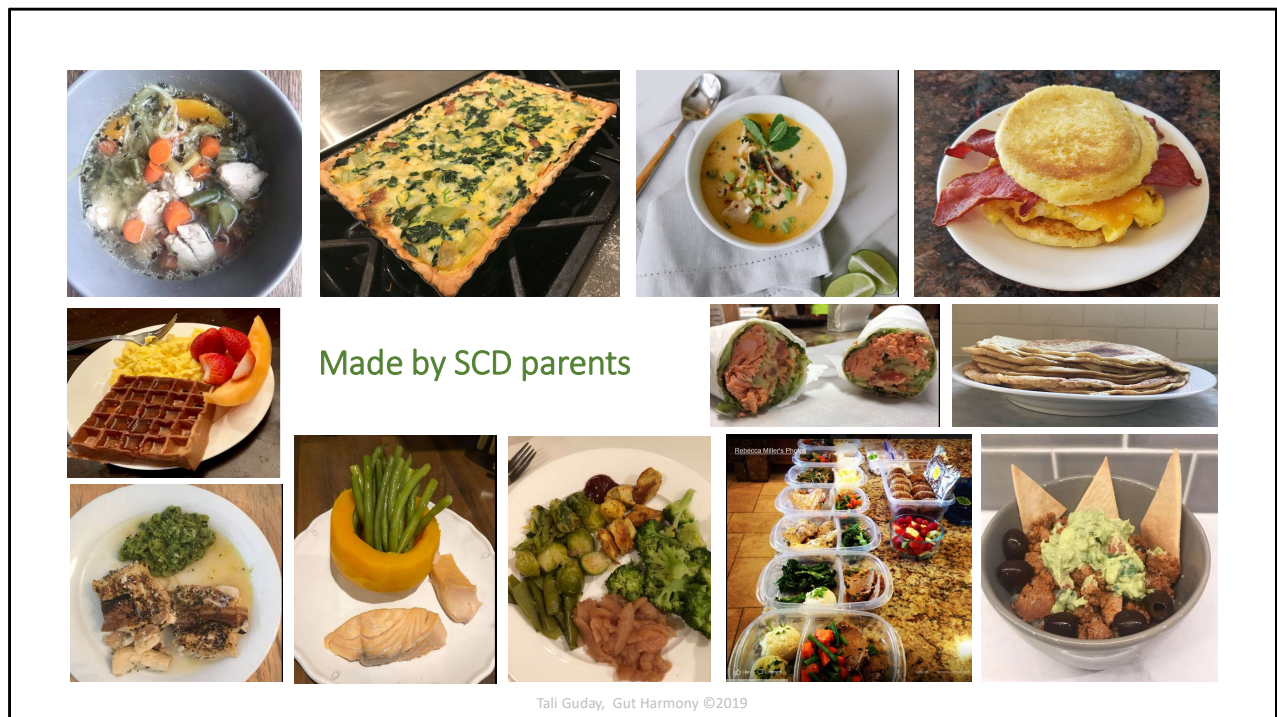
- Life without pizza? No candies on Halloween?? Aren't whole grains healthy for us???
- There is no deprivation – although there may be a **perceived** sense of deprivation



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This is how people imagine a restricted diet: chewing dry chicken feels like eternity, right?

Well, I can tell you – this diet has its challenges, but deprivation is not one of them. The food is delicious.

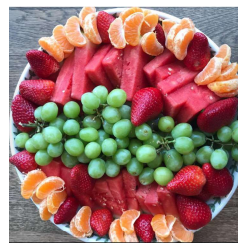


This is a random collection of photos of the foods we prepare – all photos are from the SCD families support group.

Our food is not always plated as nicely... When we feed the kids in the car on the way to soccer, we put these foods in plastic bags and disposable boxes – but it can always taste good.



Enjoyed by kids



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Homemade treats



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Command central – the kitchen

- Organize kitchen space
- Plan ahead
- Involve your kids
- Batch cook and freeze
- Label everything (dish name and date)
- Pay attention to food plating
- Give dishes creative names
- Have fun in the kitchen!
- Learn 5 minutes kitchen workouts



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Have fun in the kitchen! (listen to energetic music or favorite podcasts, keep planted herbs or flowers, maintain good lighting, nice towels, a funny apron...)

Learn 5 minutes kitchen workouts – refresh and recharge during long cooking sessions

For Example: Kitchen Pilates:

<https://www.youtube.com/watch?v=4ob2pdBH5TA>

<https://www.youtube.com/watch?v=KE5laJ1hn8c>



Posts like this are common in the group... It's a trigger topic for us... The secret wish of every SCD dieter is to have two dishwashers.

And here is another post from the group: *the SCD fridge... like trying to find a rutabaga in a haystack... no, seriously, I REALY have lost my rutabaga... 🤔*

Is the diet expensive?



- In the short term, junk food diet is cheaper than a healthy diet.
- Long term, expensive food is still cheaper than medications & hospitalizations.
- Resourceful parents find creative ways to save on food expenses and share tips amongst themselves



Which one is subsidized by us?

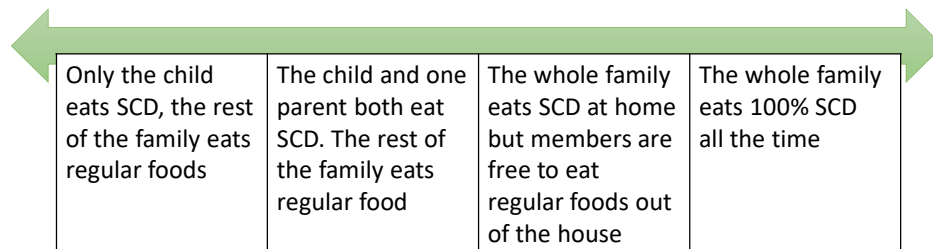
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Buy in bulk, buy on sale, buy local when possible. Order meats, eggs, honey and vegetables from local farms when possible.

We do save by not going to restaurants as often... and we re-prioritize our expenses...

Should the whole family eat SCD?

It depends on the child's emotional sensitivities and age, on the family budget, on the ages of siblings... each family choses a path that works best for them.



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There are many ways to go about it, every family decides based on many variables. As a matter of fact, it is not uncommon to have several different diet variations for different family members ...

Restaurants

- Paleo and Keto trends, as well as Whole 30, help with the availability of reasonable SCD options.
- Call ahead and talk with the chef if possible
- You have to get SUPER SPECIFIC with your waitress.
- Chain restaurants have more of their food pre-made so are harder to customize.

Truth to be said: no matter how resourceful you are - this is one of the biggest challenges in practicing diet therapies!



All true, but it is so nice to have someone else cook, serve you, and remove the dirty dishes.

My teenager usually eats beforehand or takes his own food with him. His friends understand and he's just happy to hang out with him. Occasionally he'll eat out if it's a steak or seafood restaurant, ordering steak/fish and veggies.

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We really make better food at home, but when we have to eat out...we try to make good choices, but it is not ideal.
Homemade food is always superior.

Travel – prepare like a military campaign

- Plan a menu for each day of the vacation,
- Spend a month in advance cooking, baking and stocking up the freezer
- Leave extra food in the freezer at home, so when you return tired you have a day or two covered.
- A condo, airbnb or hotel room with kitchenet are a necessity
- Research ahead and locate stores in the area (Whole Foods, Trader's Joe's, Natural Foods stores, farmers markets...)
- Check TSA and local country food transport regulations



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Thermos bottles of yogurt fill Morana's suitcase just before flying for a two week vacation.

Anyone cares to guess what is in the suitcase?

This suitcase belongs to my friend Morana. She has a son with Crohns, they live in Switzerland, and this is how they travel. These are thermos bottles full of SCD yogurt for the duration of a trip.

As a matter of fact, when my own son traveled to Berlin, Morana sent yogurt for him from Switzerland to Berlin...

Cheating on the diet

'Anxious- Furious- Hopeless! My 16 yo son ATE SOME POP TARTS HE BOUGHT LAST NIGHT!!!. I work full-time, I am getting advice from you all, researching recipes, cooking, trying to keep him on track, and I am exhausted.'

'I hear you. They have no understanding of the amount of work we invest in them. And really- freaking Pop Tart? For my kid it's damn cheese doodles and Sprite.'

'Going through the same thing now with my son. I'm going to keep cooking scd. Even though it is so much time and money. I feel that I am setting an example by staying the course. Plus, I know too much now, and could not offer him non-scd foods. I never want a thank you. I'd just like to never sleep in the hospital again (because I didn't sleep there -it was impossible)' 😊



'You have shown him some of the possibilities. Even if he is not able to commit to the diet at this time, that knowledge will be valuable for him in the future.'

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We all have complicated relationship with food. Add the complexity of IBD, the social aspects of food, the delicate power balance of parent -child relationships, and it gets complicated...

What you see above is part of a real conversation between SCD parents. This topic comes up often.

One trick that I suggest to parents is to collect articles on elite athletes that use restricted diets to enhance performance and to connect the diet to high performance instead of illness.

Make it a game



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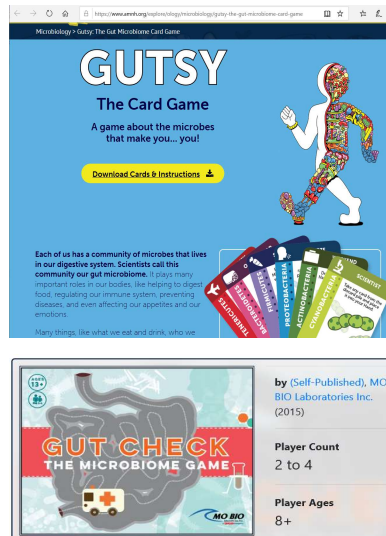
Games allow us to engage kids in open minded conversations about diet in a relaxed atmosphere.

Kids, especially teens, don't always like to talk about diet and poop... Games are a great way to defuse the tension.

Instead of arguing or preaching, the conversation around games is more relaxed and allows us to engage kids in open minded conversations about diet.

Parents also use phone apps to record symptoms or watch cooking shows together as additional ways to avoid parent-child conflict.

Scientifically accurate games are available for teens and adults



Pathogenesis deck-building game, released in 2017.
Reproduced with permission from WIBAI Games.



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JAMA - review of Pathogenesis - A New Deck-Building Game

<https://jamanetwork.com/journals/jama/fullarticle/2685131>

The Arts and Medicine June 19, 2018 JAMA. 2018;319(23):2364.

doi:10.1001/jama.2018.1770

GUTSY A fun and scientifically accurate game. each player attempts to develop a healthy microbiome while interfering with the microbiomes of their opponents.

Final thoughts...

It is always a process. Whenever you feel you have mastered the ideal way to practice the diet, your child transitions to the next stage in life and new challenges arise.



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This is how one mother from the group summarizes it:

"The beginning feels like learning to walk. A few steps forward, maybe a few back. You sometimes drop to the ground because the burden and the blessing are too much to bear. You pick yourself back up though, because that's what we do for our children. We dust ourselves off and say "we can do this. We can figure it out!"

At the SCD Families group we have: children who thrive on diet alone and children who combine diet and medications.

We also have children with additional health conditions who use the diet and have seen improvement not just in their IBD symptoms, but also in arthritis, skin eczema, type 1 diabetes, etc.

Diet teaches us to listen to our body. It gives us a sense of control –something we can do that clearly helps quality of life.

This diet, with all the restrictions, actually allowed my son to have a normal happy childhood. It is a humbling process, and it is absolutely amazing to realize the power of food.