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Autism and controlled eating: making sense of food and feeding

This article talks about food quite a lot. It's unavoidable. I'm writing about eating and I can't escape the fact that this requires the mentioning of many food stuffs. You might want to make sure you have a snack accessible.

I can't escape food. It's ever-present, necessary and fundamental to my ongoing existence. And society is *obsessed* with food. Every day the media presents a new (or recycled) headline about a rogue/super/cancer-causing/death-inducing/life-extending food type. I can't get away.

I like food. I don't love it universally. But I do like some of it. Only, it's not as simple as that. There's different foods. There's different combinations of foods. There's different ways to eat those foods, and different times when you're expected to consume them. And suddenly, the idea of eating, and the enjoyment of that task, becomes a lot more stress-inducing. Eating a limited diet is commonly reported in autistic people ([Shea, 2015](#)), which is hardly surprising when you start to consider all of the unknowns that it involves.

Let's start with different foods. There are five main tastes: sweetness, sourness, saltiness, bitterness and savouriness (umami). Reasonably simple? In principle, yes, but in reality food literally has a life of its own. An apple 'should' be sweet, but can be tart or watery. Tomatoes can be sweet or sour or savoury depending on their ripeness and type. There is anticipation in my tongue, even when I am about to eat something that I love. I don't know quite what it will taste like until I have tried.

Manufactured food is also not without its fluctuations. Take the most uniform of crisps, Pringles. Each one has a varied amount of seasoning. There is an unknown quantity even in a consistent product. I know and anticipate this difference in food. It doesn't stop me eating, but it does give me a momentary hiccup in my brain. There's a small mental intake of breath as I steel myself for the unexpected taste.

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As well as tastes there are textures. I find soft foods really hard to sense in my mouth. There are no edges, no spatial boundaries that enable me to work out where it is and what I need to do with it. It's really easy for me to gag if I have these sorts of foods, which means its very tiring to try and coordinate every single mouthful from intake to swallowing:

- pick up spoon
- scoop food on spoon
- lift to mouth
- put in mouth
- hold food in mouth
- don't breathe
- try and contemplate enjoyment of this food
- and swallow.

And it's also embarrassing if it occurs. When I have to eat softer foods, I try and use a teaspoon. The small spoon means I get the right amount to fit into my mouth (otherwise I have to add in another 'scoop right amount of food on spoon' stage, which is impossible to work out). For some reason, society expects adults to eat from desert spoons or some weird sized spoon slightly smaller than that. Either way, they're too big. Yes, it might take me ages to eat, but I can feel more comfortable and won't end up spraying yogurt all over the place.

I like crunchy foods, things with edges that I can feel on my teeth, tongue and mouth. I know where the food is and that it won't unexpectedly try to choke and kill me because I won't forget it's there. It's another reason I prefer cutting up food into smaller pieces. I can pick up a piece of fruit with a fork (in public) or my hands and know it will fit into my mouth and can be chewed up and swallowed relatively easily.

Generally, I prefer meals that minimise cutlery. One spoon or fork is preferable. Coordinating food from one hand to my mouth is hard enough without having to do pushy-cutty things with two utensils first. In addition, they are clattery and make squeaking noises on plates. With my hands, I have a much better sense of where the food is, and also feel more connected to it. If I am connected to the food, this makes it safer to me and easier for me to eat.

Flavours, textures and methods of eating mean that simple combinations of foods are much more accessible. It's very rare I will actively choose to eat a one-pot dish, unless it has very basic flavours. There's too much diversity in taste and texture and it becomes an overwhelming chore.

Biting into whole foods is an unknown quantity unless I nibble. And if you think eating with a teaspoon is unacceptable, then nibbling definitely qualifies. I've tried to train my teeth to make even bites and mouthfuls but they won't. There's always a risk I'll end up with a huge mouthful I can't manage, or bits of food will fall out.

I probably sound like an atrocious eater. I'm not the most coordinated at home, but that doesn't matter because I'm in my own environment and can eat the foods I am comfortable with in the

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way that I need, without it being questioned. I hate eating in public but because of my job I sometimes have to eat while travelling or during meetings.

For some reason, there are a number of people who seem to think that whatever and however you're eating is fair game for them to comment on. I don't care who you are, I am not going to bond with you if you start nit-picking about the contents of my salad or act disappointed because I didn't want one of the jam doughnuts you offered me. Saying 'no thank you' apparently means I have rejected you personally. I haven't, I just don't want a cake that looks like it should be on a mortuary slab. And my food is mine. I'm not forcing it on you. It's challenging enough for me to be eating it around someone else without you distracting my brain and making me feel as though I'm doing something less than normal. Yes, it might be different, but different is not wrong!

I have built a repertoire of foods I am more comfortable with, that are less challenging to my brain and tongue. I think this is reasonably broad, although others find it surprising I can have the same evening meal three or four times a week. But it's not the same meal to me as it will always taste and feel a bit different while I am eating it. And even if it didn't, what's wrong with sticking to things I feel comfortable with? When I've had a really anxious day, the last thing I need is to heap more stress on my head by challenging myself to eat a dessert spoon of mashed potato. Don't judge my level of diversity against yours, but understand how much of an adventure each mealtime is even with the same ingredients.

Over a decade ago, I spent several months at a day unit for people with eating disorders. I'd had a breakdown and controlling my eating was one way of managing the massive amount of anxiety, fear and distress I was experiencing every day. There is some evidence that females on the spectrum may be more at risk of developing anorexia (Kalyva, 2009).

I never stopped eating, but the quantity and types of food I was able to eat shrank drastically and so did I. I was supported through psychotherapy and a supervised eating programme. Food was the only thing I could control, so the idea of this being taken away was impossible. My initial stint at the clinic was not successful and I very quickly relapsed. I was not allowed to eat with my hands. I couldn't eat small bites. I had to try lots of different types of food to 'challenge' my eating disorder. I couldn't wipe my hands on a paper towel while I ate. I had to eat in a room with 10 other people, with lots of noise and hugely heightened emotions. I had to talk about how I felt about the food.

My reluctance, non-compliance and (in the case of the latter) complete inability to do these was seen as not engaging with the programme or challenging my anorexia. I appreciate how it must have looked, but my reality was very different. Wiping my hands stopped them being sticky – a sensation I absolutely hate and dominates my brain until I can get rid of the sensation. Small bites meant I could process each mouthful. Eating with my hands made the food safer...these were ways I had of coping with eating, they weren't barriers but quite the opposite. However, they weren't deemed to be 'normal' and therefore couldn't be allowed.

The difference came with my second admission. I had a key worker who listened, who took my descriptions of my fears of eating and worked with them for what they were. She didn't try to

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put them into a box marked 'weight restriction/body image'. I didn't have a diagnosis of autism at this stage and didn't have any sense of my own awareness of my needs - what was important was that she took time to get to know me. I was able to wipe my hands. I was able to take small bites and cut my food into small pieces. Suddenly, I was being supported to use the skills I already had to manage food, to help me to expand my comfort zone and better learn to look after myself.

Now, I don't describe myself as 'recovered' but I also don't really consider the eating disorder label was applicable. Yes, I had weight to restore (and I've done so), but actually I've accepted that I will always need to control my food to some degree. This may be for sensory reasons, or it may be because I am particularly anxious about something and need to have a safer meal in my stressful day. When I am anxious or stressed, food challenges are overwhelming. Any food feels too onerous to contemplate. I don't want to eat, not because I am scared of the food, but because I am scared of processing every single pre, during and post-eating sensation and thought spiral. It's exhausting and takes any enjoyment out of the act of eating.

My autism diagnosis is recent and eye-opening. I can start to offer myself acceptance with my eating quirks. I can be tolerant of the days when I don't enjoy food, and make sure I have safer meals before and after busy days away. I can enjoy what I eat in the way that I eat it. I am losing the criticism I had of myself. I still work to be open to my challenges and how I can support myself to manage different situations. I am helped to do this by people around me showing acceptance, a lack of judgement and by not getting upset when I refuse their doughnuts.

References:

- [Shea, E., Understanding and Managing Eating Issues on the Autism Spectrum', Network Autism, 3 February 2015](#)
- Kalyva, E. (2009). Comparison of eating attitudes between adolescent girls with and without AS: Daughter's and mother's reports. *Journal of Autism and Developmental Disorders*, 39(3), 480-6