PEAS Presents:
Eating, Feeding & Swallowing for children on the Autism Spectrum: Getting the info and figuring out what to do with it | Oct 26 & Nov 2, 2022

Joint Presentation: AHS Glenrose (GRH) & Holland-Bloorview Rehabilitation Hospitals

Additional Questions (not answered live)

1. **I am very interested in the role of the vagus nerve in eating.**
   Thanks for your comment. While this is an interesting area, it was outside of the scope of this presentation.

2. **Do you use Food Pro or other nutritional analysis software when you are obtaining food records from your clients?**
   From Glenrose Registered Dietitian: We do use Food Pro (11.9) on a case-by-case basis, especially if food repertoire is very limited.

3. **I work in a specialised ed setting and frequently have students with PFD and When I explore the issues I very frequently see signs of chronic constipation, and also swallow, or esophageal discomfort. Around swallow and esophageal issues the instrumental assessments are so challenging for these kids. Advice on those assessments?**
   I agree that it can be very challenging to have children with ASD participate in VFSS. We have a visual story about VFSS that we can email to parents/therapists in advance to help prepare. If we know in advance that a child may have a lot of difficulty participating we can have them come to the Glenrose to see the VF suite before their assessment for a 'practice run'.

4. **With constipation and the medication connection, are medication motility supports alongside stool softeners a recommended protocol?**
   Recommended protocol/guidelines for the assessment and management of constipation in the context of autism spectrum disorder:
   https://publications.aap.org/pediatrics/article/130/Supplement_2/S98/30533/Management-of-Constipation-in-Children-and

5. **Does P-SROP see children from across the province? If so, how can we place a referral or does it need to come from the Glenrose?**
   P-SROP sees children from the Edmonton Zone, North Zone and some of Central Zone (north of Red Deer). The child needs to be assessed through Glenrose Feeding/Swallowing outpatient clinic first, then our team will refer to SROP.
   Note: PEAS has a Service Directory Eating, Feeding & Swallowing Services here:
   https://peas.ahs.ca/page/10414/AHS-Services#none

6. **Strategies for acceptance of vitamin mineral supplements? Also what multivitamin mineral supplements do you recommend when more than single supplement is warranted?**
   We know that autistic children and youth are more likely to have low levels or deficiencies in iron, Vit B12, folate, Vit D, protein and calcium. As such if supplements are considered there are a few factors to consider; i) if presentation/consistency – liquid vs tablet vs capsule vs gummy; ii) can the child or youth swallow a pill; iii) does the child/youth have olfactory hypo/hypersensitivity and iv) which micronutrient is this child most likely to be deficient in based on dietary intake. Remember excessive micronutrient intake may also have side effects and place the child at risk for toxicity. Speaking with a pharmacist/dietitian would be best to identify which supplement would be best for the child/youth.

It is easy to suggest a supplement, but not as easy to get children to take them especially if multiple are needed. Start with the one that is most needed based on bloodwork or diet history. Work with parents to determine what presentation might be best for the individual child (drops, liquid, chewable, gummy). It may be that it takes time to work up to a therapeutic dose so start slowly so the child can gradually get used to it rather than the full dose all at once. If a child is very limited, avoid hiding it in a safe/preferred food-there is a risk that they will reject that food/liquid moving forward. At times, a nutritional supplement drink is recommended rather than individual supplements. Again, it may take time to work up to the full recommended volume.

7. **For a lot of children the Dx of ASD does not typically happen until very rigid feeding practices are already in place. It is hard to reverse some children. In acute care we have an increase of children in feeding strikes with no intake of food or solids until nutrition support through NG feeding becomes mandatory. I wonder your thoughts on use of NG for these children on future feeding skills, or for children who refuse oral supplements.**

   The role of NGT is to ensure a child/youth is receiving adequate nutrition to sustain life, this is a medical intervention. When oral intake is limited, inadequate and contraindicated then an NGT is considered. The NGT can be used as a tool for weight and nutritional restoration/rehabilitation with a goal of oral rehabilitation. However, there must be a good plan and supports in place to work towards better oral nutrition. The NG tube will not change the underlying reasons why a child is not eating. A Gtube may be considered if it appears that the child may need nutritional support longer term. But again, the goal should be to put a therapeutic plan in place. Working towards the acceptance of oral supplements is a good goal, but will require a good assessment to try to determine the reason for refusal.

8. **Is there a threshold number of foods to indicate that a client may have a limited food repertoire?**
   There is truly no specific number of foods identified in the literature that gives a "cut off" for limited food repertoire. We focus more on the quality of foods being consumed. If a child has only a few foods but one of them is a supplement like Pediasure then they are likely doing better nutritionally than a child who is eating 15 different carb loaded foods with no protein/dairy etc. It is the nutritional/medical assessment that comes first, if concerns identified on bloodwork or through nutritional workup then there is concern. If the child is eating a small but varied diet and bloodwork/nutritional workup does not identify deficiencies then there is less concern.

9. **As a psychologist who works on a feeding team, in the vast majority of cases we see - lack of perceived hunger is usually connected to parental pressure. Once parents stop pressuring, kids start recognizing their hunger cues.**
   Thanks for your comment. We are glad to hear that you are having success with this strategy, We have definitely had similar experiences with some cases. We have also learned that for some children and adults, their sensation of hunger is different, regardless of the presence of parental pressure and I think this is what has made us feel that it is important to share the information about how interoception can impact feeding.

10. **What strategies do you find most helpful for gaining cooperation during VFSS?**
    See answers to question 3. We have a parent or caregiver present with the child (wearing appropriate shielding). We do a lot of singing/dancing/being silly to help kids participate. We will ask parents to bring their favourite technology (phone, tablet) to distract them. We use

rewards like bubbles or fun toys (have you seen the Minions Fart Gun?) In addition to all the things we do, we also try to make strategic decisions about what stimuli will offer and how. We want to use flavours/foods that the child will accept, however if we are concerned that adding barium to an accepted food will cause them to drop that food, we may try with a less-preferred food (ex: if Chocolate Pediasure is a staple, we might try regular chocolate milk instead). When possible we try to use opaque drinking containers or put our barium fluids back into a juice box, etc. We have also syringed barium puree back into a food pouch.

11. **Hypermobile Ehlers Danlos Syndrome (which can contribute to GI issues such as IBS and 'leaky gut' syndrome, as well as oral motor issues such as jaw instability) seems increasingly to be shown as prevalent in the population and commonly co-occurring with ASD (e.g., https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7711487/). Are certain 'better-established' medical/genetic comorbidities like this given specific consideration under the model?**

    Thanks for the great question. The MOBSE approach is not meant to focus on specific medical conditions or diagnoses but rather is meant to prompt clinicians to gather a complete medical history and to consider whether any comorbid conditions may be impacting on feeding. We have had several children recently who have ASD but also have conditions such as Celiac, EoE, Crohn's and other significant GI issues that were impacting on their feeding.

12. **When would be an appropriate time for Community Therapist to support a referral for SROP intervention at GRH?**
    If you have been working with a family for a while but feel like there might be something else going on or if you feel 'stuck' and need a second opinion, please feel free to reach out to the Glenrose Feeding/Swallowing Clinical Leads to discuss the case and see if the child would be an appropriate referral. Because we are a tertiary level program, we request that community therapists come to us with specific questions or areas of concern to address. We also require a physician or nurse practitioner order for referral to our program. Here is the link to our ARD profile and referral form: Alberta Referral Directory - Service At Facility Data Entry

13. **At what point would you recommend iron supplementation, what iron doses would you recommend?**
    Iron supplements are recommended when a child/youth is at high risk for iron deficiency anemia and if the child or youth has lab evidence of iron deficiency anemia. Ferrous sulfate is commonly used. Please speak with a doctor before talking iron supplements to ensure that the child/youth is not allergic to ferrous sulfate. It is important that the child/youth health professional review side effects. Accidental overdose of drugs that have iron in them is a leading cause of deadly poisoning in children younger than 6 years of age. Keep away from children. If this drug is taken by accident, call a doctor or poison control center right away.

    Iron deficiency anemia prevention
    WHO recommendations:

    Areas where anemia prevalence ≥40%:

    Children 2 to <5 years: Oral: 30 mg **elemental** iron daily for 3 consecutive months in a year (WHO 2016b).

    Children ≥5 to 12 years: Oral: 30 to 60 mg **elemental** iron daily for 3 consecutive months in a year (WHO 2016b).

Adolescent menstruating patients (nonpregnant patients who may become pregnant): Oral: 30 to 60 mg **elemental** iron daily for 3 consecutive months in a year (WHO 2016a).

Areas where anemia prevalence 20% to <40%: Weekly intermittent dosing:

Children 2 to <5 years: Oral: 25 mg **elemental** iron once **weekly** for 3 consecutive months, then alternating 3 months off supplementation, 3 months on supplementation. (WHO 2011).

Children ≥5 to 12 years: Oral: 45 mg **elemental** iron once **weekly** for 3 consecutive months, then alternating 3 months off supplementation, 3 months on supplementation. (WHO 2011).

Iron deficiency anemia

Iron deficiency anemia, treatment: Infants, Children, and Adolescents: Oral: Initial: 3 mg **elemental** iron/kg/day as a single daily dose (Oski 1993; Powers 2017; Reeves 1985) up to 60 to 120 mg **elemental** iron once daily (AAP [Kleinman 2019]); higher doses may be needed in select patients; dosage range: 3 to 6 mg **elemental** iron/kg/day in 1 to 3 divided doses; usual maximum daily dose: 150 to 200 mg **elemental** iron/**day** (ASPEN [Corkins 2015]; Kliegman 2020; Zlotkin 2001); once-daily administration may be preferred for ease of administration and adherence (Zlotkin 2001). Studies in iron-depleted adults suggest that iron absorption may be improved by less frequent dosing (alternate-day dosing, or once daily versus multiple daily doses) (Moretti 2015; Stoffel 2017).

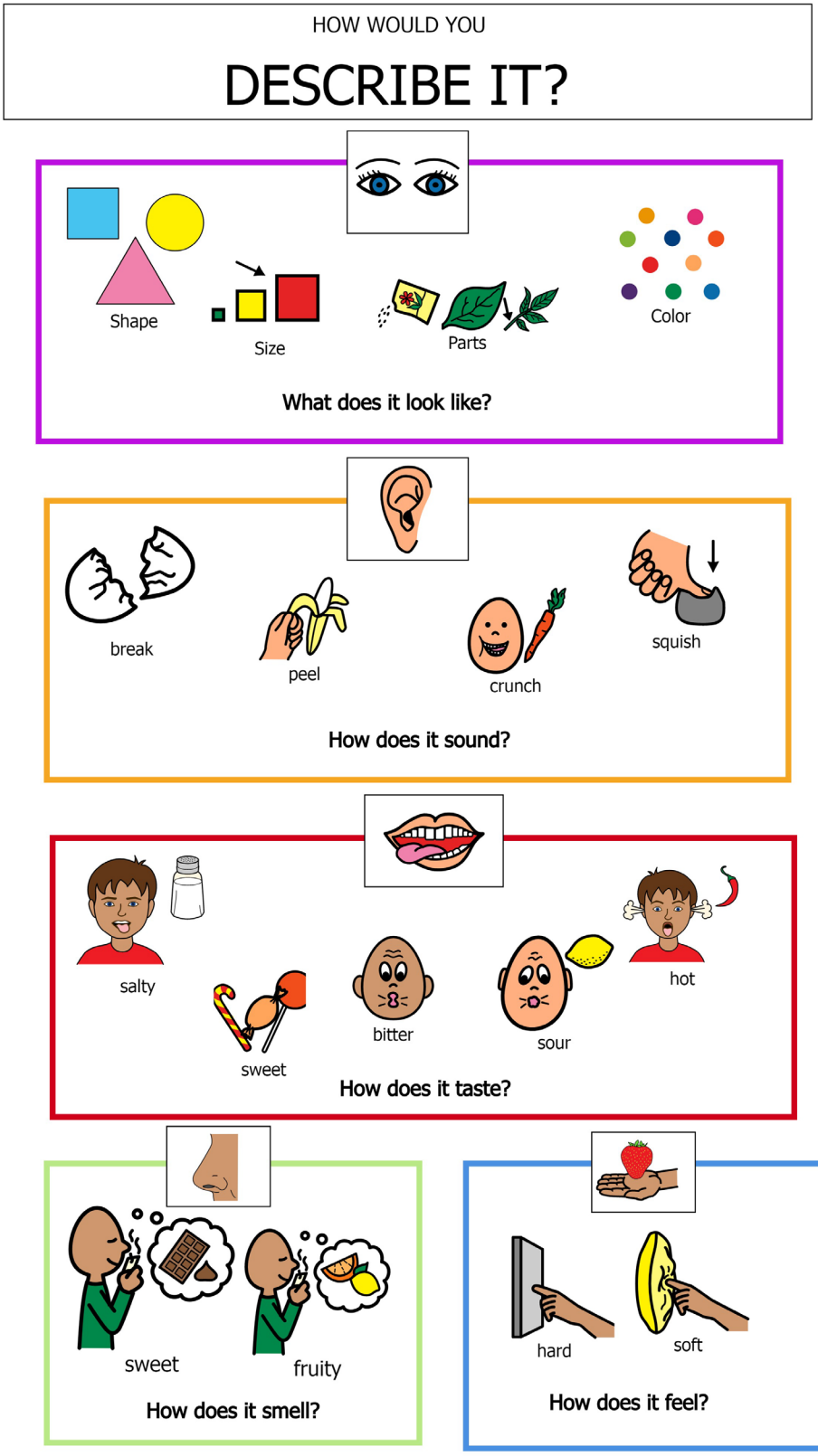
14. **Is there an example of the Describing Chart, or is it just a list of describing words for each child to learn and use?**
The describing chart is a visual aid to facilitate communication and language learning when interacting with food using the senses and learning about food in general. It is modified for each child based on their interests and challenges. We often change the words based on child/family preferences and tendencies. Here is an early chart we used for our case study. The first page can be used on its own but if need be, the chart can go more in depth through different interactions using the senses as you see in the Appendix of this document.

15. **Hi, I'm a registered dietician in Quebec City (so excuse my English). I'm seeing a 14 year old patient in my private practice who has been losing weight lately, reducing her portions because she has anxiety related to vomiting, also had lots of stressors in the last year. She also has ADHD and take Vyvanse (meds) which is known to reduce appetite. She won't take more than 3 meals a day and is always eating as little as possible. She already has meds for anxiety. Would you suggest starting with adding snack, or adding calories/proteins to the existing meals? What would you suggest as treatment course. Thank you**
From a psychology perspective – if this youth isn't already connected with a psychologist, I would recommend timely referral to investigate/address emetophobia (fear of vomiting). The typical treatment for this condition is CBT/ERP (Exposure and Response Prevention). Therapist might also want to consider ruling out OCD by determining if there are unusual or irrational thoughts related to instances of vomiting, or consistently intrusive thoughts that lead to compulsive behaviour. CBT-AR (CBT for ARFID) also could be a helpful approach as there is a module to address the fear of vomiting (exposure approach) and also consider the eating behaviours/challenges more broadly.

From a nutrition perspective, in the context of weight loss it would seem reasonable to aim to increase the calories/protein to the existing meals the patient is willing to eat. In addition, it would be important to consider scheduling consistent intake throughout the day as anxiety and medications can interfere with relying on regular hunger/fullness cues. However, it would be important to work with the patient and involve other healthcare professionals as needed to address underlying reasons for restriction.

16. **I have tried "counting competitions" on how long a challenging food can stay in our mouth/tongue etc. Wrong? or is that ok?**
Distraction can be very helpful for desensitization - similar to using motivating activities to increase opportunities for exposure. Once the child experiences success with "easier foods", the game or competition could also be paired with a reward (positive reinforcement) for more challenging foods or longer exposures. Often, praise from the therapist/parent is highly motivating but tangible reinforcement adds another level of motivation.

Appendix



Alberta Health Services
Pediatric Eating And Swallowing

Holland Bloorview Kids Rehabilitation Hospital

What does it **LOOK** like?

What **SHAPE** is it?


square


circle


triangle


diamond


rectangle


cylinder

What **SIZE** is it?


big

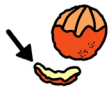

medium


small

What **PARTS** does it have?


seeds


stem


orange peel


leaf

What **COLOR** is it?


blue


green


orange


pink


purple


red

yellow


black

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