“What’s on Your Plate?”
Understanding Nutrition-Related Challenges to Creating Healthy Eating Habits for individuals with Down syndrome

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The Journey
Objectives

- At the end of the presentation, learners will be able to:
  - List specific nutrition-related concerns for people with Down Syndrome.
  - Describe one action step for each one.
  - List one next step for their family to teach nutrition skills.
Nutrition-Related Concerns

- GERD: gastro-esophageal reflux disease
- Constipation
- Celiac Disease
- Diabetes
- Sleep
- Weight
- Long-Term use of Medications
Nutrition-Related Concerns

- **GERD**: gastro-esophageal reflux disease

  GERD is when the contents of your stomach (acid) push backwards (up) toward your mouth.

  - Often “silent” until there is a crisis due to pain.
  - The observed “crisis” is often behavioral.
Physical Symptoms of GERD

- Persistent cough
- “Wretching”
- A second taste of the meal
- Hoarseness
- Asthma
- Difficulty swallowing
- Loss of enamel on teeth
- Poor sleep.
- If not treated, appetite may decrease.

Some **Behavioral** Symptoms of GERD

- Not able to sit or be still after meals (usually a complaint that comes from school)

- Irritable, especially in the hour or so after meals.

- Withdrawal, depression, or “regression.”

- Poor sleep.

GERD: The Nutrition Plan

Things you can do to help with GERD:

- Encourage and teach appropriate portions.  
  **Goal:** reduce overeating at a meal.

- Reach and maintain an appropriate body weight.  
  **Goal:** Evaluate activity and eating habits to reduce weight.

- Watch for trigger foods.  
  **Goal:** Once you learn the trigger foods, remove them from the menu to help reduce reflux.
  - Keep an eye on caffeine – a common trigger.
  - Keep an eye on carbonated beverages – a common trigger.

- Spend time with the person before bed time.  
  **Goal:** Eliminate late night snacks.

- Manage Constipation  
  **Goal:** to keep constipation under control so it does not trigger reflux.
Nutrition-Related Concerns

- GERD: gastro-esophageal reflux disease
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- Diabetes
- Sleep
- Obesity
- Long-Term use of Medications
Constipation

- What is it?
- What’s normal?
- How do you know if they don’t tell you?
- What do I do?
  - Are they drinking enough? Diet pop can count – but try to keep it to two to avoid bloating.
  - Increase fiber
    - Dietary fiber (whole grains, fresh fruits and vegetables…)
  - Increase exercise
    - It helps with weight, but it also helps with digestion.
  - Consider fiber alternatives:
    - Benefiber, Metamucil
Celiac Disease
Celiac Disease

- Approximately one percent (1%) of people in the United States have celiac disease.

- Studies suggest that four to sixteen percent (4-16%) of people with Down syndrome may develop celiac disease. (Gale, 1997).
Signs of Celiac Disease

Notable for Down syndrome:

- **Everyone** with Down syndrome can have the gene for celiac disease.
  - Those without Down syndrome need family history.
- A key overlooked symptom: “regression in skills.”
- Can have constipation or diarrhea, or anything in between.
- Anemia.
- Lactose intolerance.
- Low vitamin D
- Screenings may be “inconclusive.”
  Don’t forget professional judgment.
Treatment: A Gluten-Free Diet
Some hints from the GF Trenches

- It’s great to see your child get better with a healthy gut.
- Keep an eye out for constipation.
- Consider an over-the-counter multivitamin.
- Be patient with new foods. Gluten-free eating can take some getting used to.
- Teach your child words of foods that contain gluten.
  - Add them to the reading list at school.
  - Use the same skills: Match – Select – Name to teach.
- Remember, slip ups will happen. Use them to teach, not preach.

Get a note from your doctor for school. Celiac Disease is a life-threatening allergy. Create a 504 plan or addendum to the IEP to instruct teachers what to do.
Nutrition-Related Concerns

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Metabolism
Burn, Baby, Burn!

- Basal Metabolic Rate decreased by 10-15%.
- Thyroid Monitoring
Let’s say Joan and I are the same height. And we weigh the same. too. … We’re twins!

If I eat a cookie, and she eats a cookie that’s just like it, it will take me longer to burn the calories from the cookie than her.

Mia Peterson
Situations that may cause weight gain

- Hypothyroidism
- Lower BMR
- Celiac Disease

- Medications
  - SSRIS (paxil, zoloft..)
  - Psychotropics: Risperidone, Geodon, Zyprexa
  - Many seizure medications
Situations that may cause weight loss

- Undiagnosed Diabetes
- Hyperthyroidism
- Cancer
- Celiac Disease
- Infections
- Unrepaired heart defect
- Increased BMR or energy needs
Medication Side Effects

✓ Ask about food-drug interactions
✓ Ask about effect on weight
✓ Watch for effect on appetite

How do you decide?

Does the benefit outweigh the side effect?
Loneliness is the only real disability.

David Pitonyak…..or….Beth Mount.
Even they can’t decide.
Let’s Talk Food
What’s on Your Plate?

Communication Skills

Physical Skills

Sensory Skills

Learning

Morris, SE & Klein, MD. 
The “Crunch” Theory

- What do most “soft” foods have in common?

- What do fresh fruits and vegetables have in common?
The First Choices

- Have immediate feedback
- Typical first choices:
  - More
  - All Done
  - No way!

Disability Solutions focus on Choice
http://downsyndromenutrition.com/dsolns-v6.html
The Power of “No, thank you” or “You’re kidding, right?”

• Builds self-confidence
• Promotes control over lifestyle
• Is traditionally discouraged through teaching techniques.
Making Food Choices

cracker

popcorn

Apple
Nutrition Education Tips

The Community Classroom

- Grouping Foods
- Setting the Table
- Wipe the Table
- Wash Dishes
- Food likes and dislikes
- Menu & Snack Planning

- Grocery Shopping
  - Find food in aisle
  - Select produce
  - Push Cart
  - Keep a list of prices

- Farmer’s Markets
- Restaurants...
Tuna Salad

Tools I need:
- Mixing bowl
- Measuring cups
- Can opener
- Spatula or big spoon
- Strainer

Directions:
1. Wash hands.
2. Gather ingredients and tools.
3. Open Tuna can or packet.
4. Put Tuna in mixing bowl.
5. Measure 2 Tablespoons mayonnaise.
7. Measure 1 Tablespoon relish.
9. Measure 1 teaspoon mustard.
11. Add shredded carrots or celery if you want.
12. Stir to mix.
13. Measure 1/4 cup of tuna salad for each sandwich or serving.
14. Put left over tuna salad in a plastic container.
15. Label with date and put in refrigerator.
16. Eat
17. Clean up.
18. You are done.

Information:
- Time to make it: 15 minutes
- This recipe makes enough for 2 people.
- One serving is 1/4 cup

Foods I need:
- 1 can tuna
- 2 Tablespoons mayonnaise
- 1 shredded carrot
- 1 tablespoon relish
- 1 teaspoon mustard

Cooking tips:
- Use a strainer to drain water from tuna.
- Grilled the sandwich to make a Tuna Melt. See page X.
- Use in a Wrap. See Build-a-Wrap on page X.
- Use as a main dish with fruit salad.
- Serve on a lettuce wrap (see picture).
- Put a scoop in the middle of a tossed salad.

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More Visual Recipes

Use Universal Design!
Teach Portion Control

- Take advantage of “The Groove.”
- Use recipe systems that reduce or eliminate leftovers.
- Use visual cues.
- Provide guidelines for favorite restaurants.

Model the expected behavior
What’s Your Plate’s Real Estate?

In focus group testing.
Available in March from DownSyndromeNutrition.com
Healthy Lives Begin Now

- **Set Household Rules**
  - Schedule Meals & Snacks
  - Eat in designated areas
  - Remember the feeding relationship
  - Use Choices
- **Plan meals for balance**
- **Trust**
“It is up to us to stay healthy, exercise, and eat well. Parents can encourage us, give us advice, and remind us now and then, but they can’t make us do anything; only we can.”

--Mia Peterson,
co-researcher and self-advocate
Questions?

Email: Joan@DownSyndromeNutrition.com

Check out the Wellness Walk @ www.DownSyndromeNutrition.com

Supporting families to create quality lives, quality health, and a community vision.

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