

Food and Nutrition for people with Down syndrome
A map for promoting healthy eating

Dreams do come true
National Down Syndrome Center

Joan Guthrie Medlen, MEd, RDN

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Today's Menu

- The foundation
- Still the top two:
 - Selective eating
 - Weight management
- Nutrition related health concerns
- Planning for tomorrow, today
- Tips to get started

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What is in the way?

Definition of Health and Safety

Choice

Person Centered Thinking

Role Modeling

Rights

Training

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The Feeding Relationship

Parents are responsible for **what, where, when,** and **how** food is presented.

Children are responsible for **how much** and **whether** the food is eaten.

Chapter 8 of The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Eating (2020)

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Support Persons


(nurse, social worker, dietitian, early intervention teacher, babysitter, respite worker, speech pathologist, occupational therapist, physical therapist, behavior consultant, grandmother, aunt, neighbor, and lady at the grocery store...)

Are responsible for **what, where, when,** and **how** food is presented within the parameters of the **family's values,** as long as it does not do harm to the child.

Chapter 8 of The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Eating (2020)

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Then as they grow... and step out on their own...



They....

- Are responsible for **what, where, when,** and **how** food is eaten...as well as **how much** and **whether or not** it is eaten.
-with our support.
- We are engineers, mentors, and...parents.

Chapter 8 of The Power Syndrome Nutrition Handbook: A Guide to Promoting Healthy Eating Habits


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Division of Responsibility
AKA: The Feeding Relationship

High Demandingness	
Authoritarian	Authoritative
Low Responsiveness	High Responsiveness
Neglectful	Permissive
Low Demandingness	

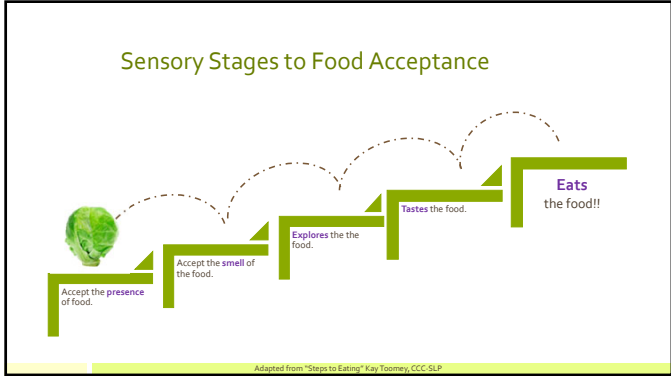
Pollack et al. Journal of Pediatric Nursing: The Influence of a Developmental Disability on the Child's Weight-Related Behaviors: A Parent's Perspective, 2013, 28, 121-130

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Selective Eating

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Moving Ahead with Foods: Matching Oral Motor Skills and Food Textures

Food Type	Pre-Feed	Puree	Thick Puree	Ground	Chopped/Small Bites	Table Foods
Chewing stages	Sucking	Sucking	Strong sucking or early sucking	Munching	Chop to move tongue to follow foods. Chew is more frequent than	Mature rotary chew
Feeding Skills to Note	Rooting	Attempts to hold bottles. Decrease in gag reflex.	Show interest in "spilling" spoon.	Decrease in gag reflex. Less cup more often. Grasp spoon to play with.	Decrease in gag reflex. Feeding and drinking with increasing independence. Foods self finger foods. Begins to try utensils independently.	Many when feeding will suckles back and forth between utensils and fingers.
Foods to Offer:	Breast milk or formula	Infant cereals should look like a "heavy, thick liquid" or applesauce. Introduce blended, strained, baby foods (Home-made or commercial).	Gradually increase the thickness of puree or strained foods by adding baby cereal, wheat germ, or potato flakes. Introduce <i>hand manhandles</i> *	Blended, cooked vegetables, scrambled egg, mashed soft-boiled egg, cottage cheese. Introduce <i>milk able hand handles</i> *	Chop regular table foods to small, fine pieces. Introduce finger foods that are easily chewed. Introduce cubed foods such as cheese.	Monitor oral-choke foods for safety. Modify the list of foods to match an individual. Introduce crunchy and chewy foods such as raw broccoli to build jaw strength.
Indications for Next Step	The beginning of a sucking motion.	Strong, well-developed sucking motion. May still have trouble keeping pureed foods in mouth.	Learns to keep thick puree in mouth. Begins to use an up-and-down chewing motion.	Side-to-side movement of food with tongue.	Beds stabilize foods for lips and fingers and feeding abilities.	
Cautions	Pay attention to choking precautions.	Pay attention to choking precautions. Always hold on to one end of solid hand manhandles.	Pay attention to choking precautions. Do <i>not</i> mix textures such as spaghetti with meat sauce or meatballs, peas in mashed potatoes, and so on.	Pay attention to choking precautions. Do <i>not</i> mix textures such as spaghetti with meat sauce or meatballs, peas in mashed potatoes, and so on.	Pay attention to choking precautions.	Pay attention to choking precautions.

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Are they really a "picky eater"?

- Make a list of all the foods the person eats.
 - Is it less than 50?
 - Is it less than 25?
- List similar foods to the ones the person eats:
 - Food item
 - Preparation
 - Temperature
 - Color
 - Texture

Food Allie Worksheet

Food my child eats, (and likes):

- French Fries
- Spaghetti
- Noodles

Foods that are LIKE the foods my child eats:

- Oven baked parsnips
- Oven baked sweet potatoes
- Spaghetti squash
- Zucchini spiral cut "noodles"

Thoughts and notes:

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Taste Testing?

Try tasting rather than strong-arming children to try new foods

- Must be done in a safe environment. (It's OK not to try something.)
- Done as a group activity with others, away from family or living situation and pressure of mealtime
- What is learned?

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Be Sense-able

- Is it hot? cold? Just right?
- What color is it?
- How does it look?
- Does it make a sound?
 - When you are making it?
 - When you eat it?
- How does it feel?
 - As you make it
 - In your mouth?
- How does it taste?
 - Bitter?
 - Sour?
 - Spicy?
 - Sweet?
 - Salty?

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My Tasting Journal

Keeping track of foods I enjoy



by Joan Medlen, MEd., RD, LD

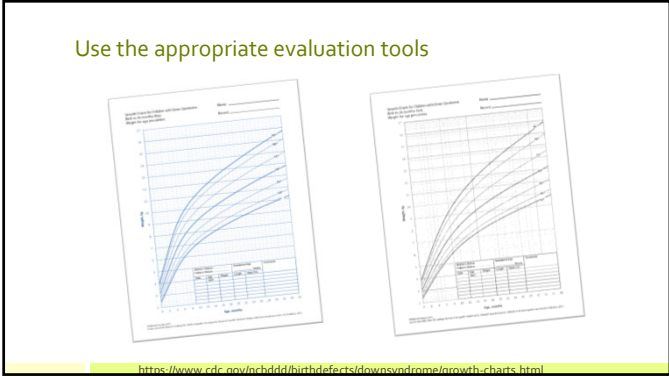
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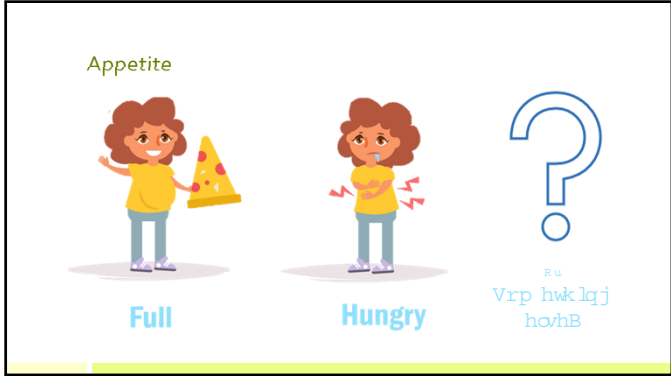
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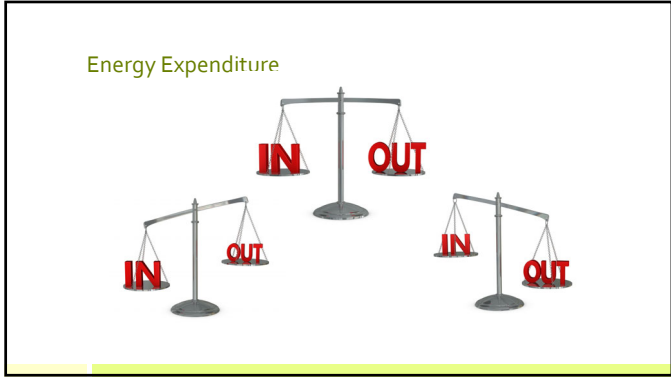
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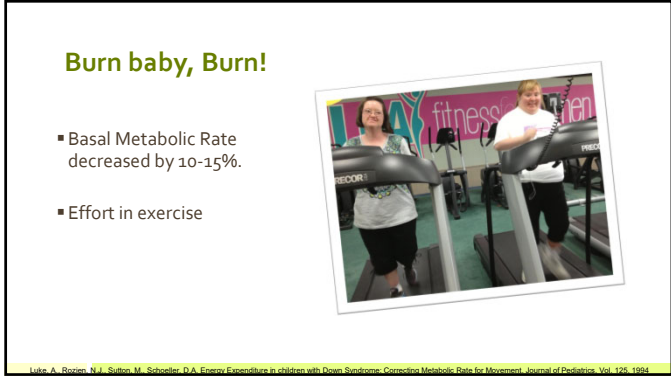
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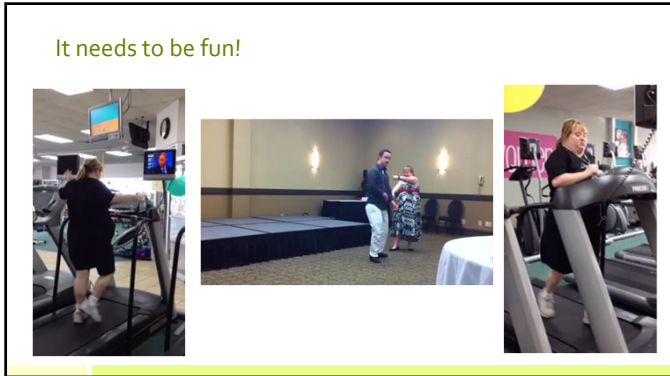
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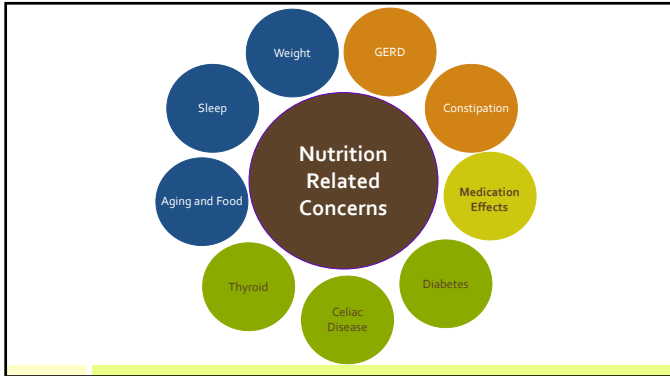
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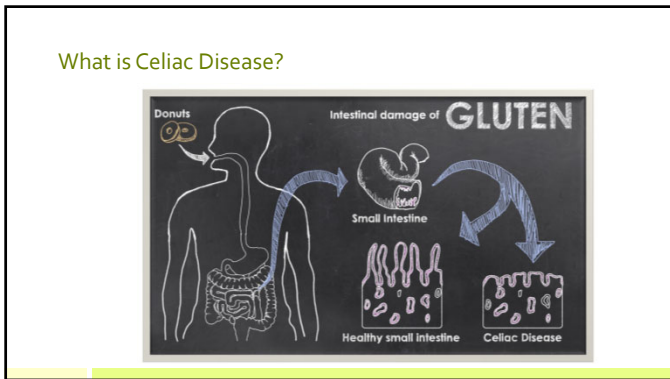
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Celiac Disease

- Approximately one percent (1%) of people in the United States have celiac disease
- Children with Down syndrome: One to five percent (1-5%)
- Adults: 11 percent (11%) of people with Down syndrome may develop celiac disease
- Health Care and Supervision Guideline for Children and Adolescents:
Review for symptoms at every visit and evaluate as indicated
- Statement of Good Practice for Adults:
Adults with Down syndrome should receive an annual assessment for gastrointestinal and non-gastrointestinal signs and symptoms of celiac disease using targeted history, physical examination, and clinical judgment of good practice⁽³⁾

(1) Real de Asua D, Quera M, Moldenhauer F, Suarez C. Clinical profile and main comorbidities of Spanish adults with Down syndrome. Eur J Intern Med. 2015;26(8):385-391
(2) Sullivan M, Trotter T, Santoro S, Christensen C, Grout R. The Council On Genetic Health Supervision for Children and Adolescents with Down Syndrome. Pediatrics (2022) 140 (5)
(3) Tatro A, Balducci D, Capone C, Chappone B, et al. Medical Care of Adults with Down Syndrome: A Clinical Guideline. JAMA (2020) 324(15): 1543 - 1556

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Signs of Celiac Disease

Notable for people with 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

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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 **gluten-free** multivitamin
- Be patient with new foods
- Teach your child words of foods that contain gluten
 - Add them to the reading list at school
 - Use the same strategies: Match – Select – Name to teach
- Remember, slip ups will happen. Use them to **teach**, not **preach**



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Food-Related Challenges to Gluten-Free Living

<p>Health</p> <ul style="list-style-type: none"> • Fat • Fiber • Iron • B-Vitamins • Growth • Bone Health 	<p>Behavioral</p> <ul style="list-style-type: none"> • Financial cost • Time cost • Compliance cost • Behavior risks
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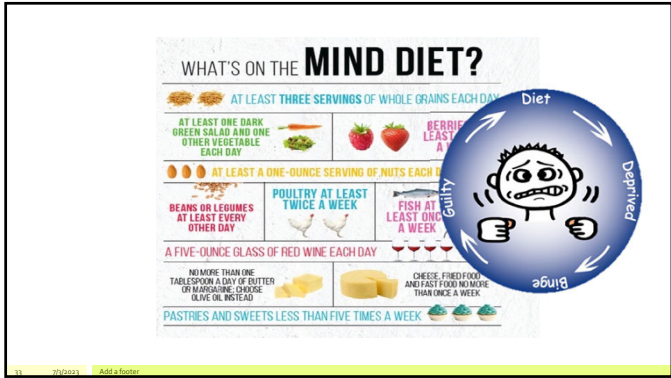
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Food Goals for the Future

- Dark, leafy greens
 - 6 times a week
- Other non-starchy vegetables
 - Once a day
- Berries
 - 2 times a week
- Fish
 - Once a week
- Poultry
 - 2 servings a week
- Beans
 - 3 servings a week
- Use whole grains
- Nuts
- Use olive oil

Morris, M, Tangraw, C, Wang, Y, Sacks, F, Baroni, L, Bennett, D, Aggarwal, N. MIND diet slows cognitive decline with aging. *Alzheimers Dement*. 2014 10(9): 1554-72

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**Food Goals for the Future:
Things to Watch**

Limit:

- Butter and Margarine (use olive oil)
- Cheese
- Red Meat
- Fried Food
- Processed Foods
- Processed foods
- Sweets
- High Fructose Corn Syrup
- Amount of sugar overall

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The Keys to Success




- Communication
 - Clear, shared overall goal.
- It needs to be understandable
- Tools need to be easy to use.
- Choice! Choice! Choice!
- Positive Behavior Support Strategies
- Support for the team:
 - Everyone must be on board.
 - Training & education for supports
- Environmental impact

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Tools for the Toolbox

- Visual strategies
- Video Modeling
- Pre-teaching
- Role play
- Repeat – Repeat – Repeat
- Grooves
- List making
- Curiosity

- Tasting
- Engagement
- Responsibility
- Support for the support (whether it's you or someone you pay)



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Make it tangible

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The Energy Equation of Change

For changes we choose:

TIME FOR CHANGE

- 5% of behavior is consciously self-directed.
- 95% of what we do occurs automatically or in response to a "demand" or anxiety.

The Power of Full Engagement

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5%?

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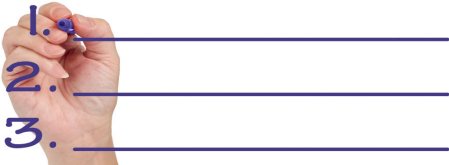
A place to begin

▪ Important to	▪ Important For
▪ What Works	▪ What does not work

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What **one** thing would you like to focus on?

Next Steps



1. _____
2. _____
3. _____

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Contact Information

Joan Guthrie Medlen, MEd, RDN, LD

www.DownSyndromeNutrition.com

Email: Joan@DownSyndromeNutrition.com

www.FaceBook.com/JoanGuthrieMedlenRD

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