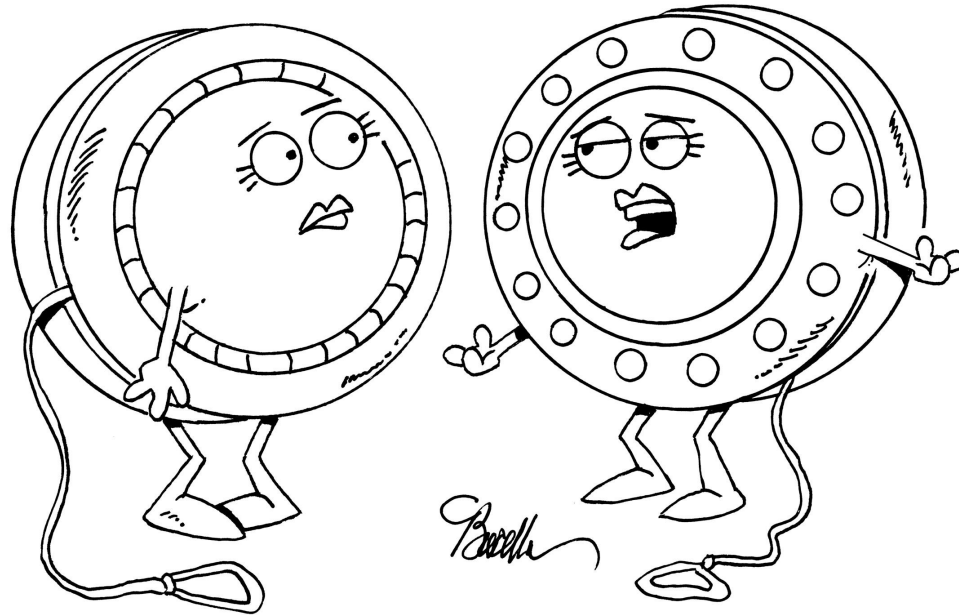


Down Syndrome Alliance Education Series:

Weight and Diet Concerns

Amy Volkman, RDN LMNT
Munroe Meyer Institute

Losing weight: diet, lifestyle, wellness?

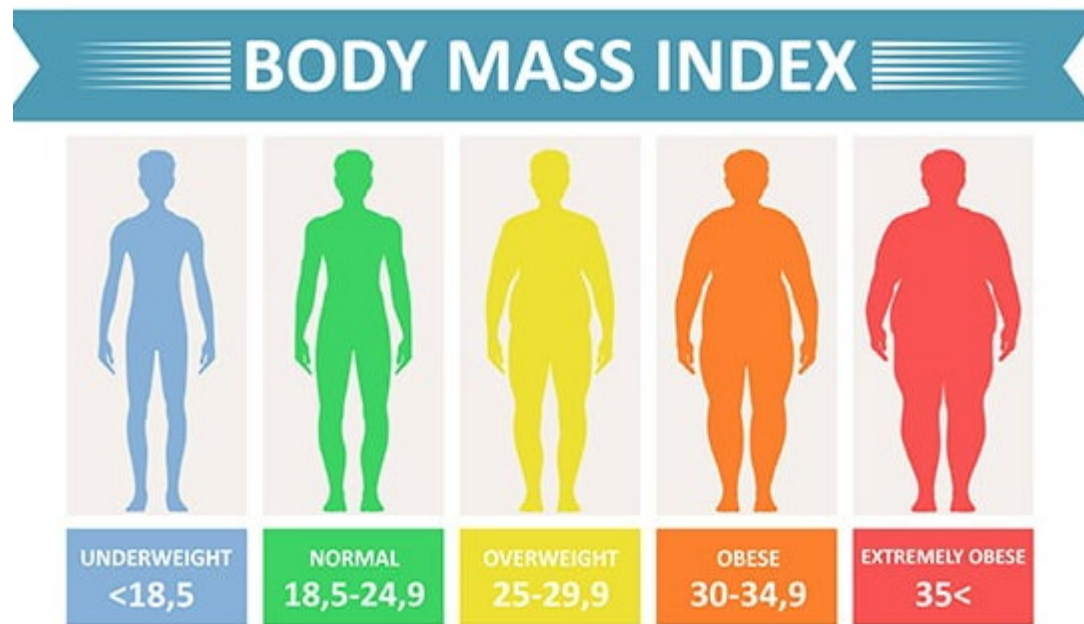


“I’ve been trying to diet, but it’s up and down
and up and down...”



What is obesity?

Based on BMI... but also it's not all about the BMI!





Why is excessive weight a concern?

- Mobility
- Sleep apnea
- Pulmonary hypertension
- Heart disease
- Type 2 Diabetes









Contributions to Weight Gain


- Executive Dysfunction
- Hypotonia
- Feeding Difficulties
- High leptin levels

Photo courtesy of Cleveland Clinic.

Executive Dysfunction

Some examples of executive dysfunction include:

 <p>Focusing too much on just one thing.</p>	 <p>Being easily distractible.</p>	 <p>Daydreaming or "spacing out" when you shouldn't be.</p>
 <p>Struggling to switch between tasks.</p>	 <p>Problems with impulse control.</p>	 <p>Trouble starting difficult or boring tasks.</p>

 Cleveland Clinic

Feeding Difficulties and Obesity



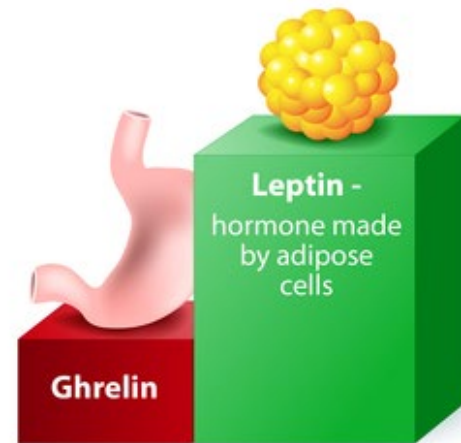
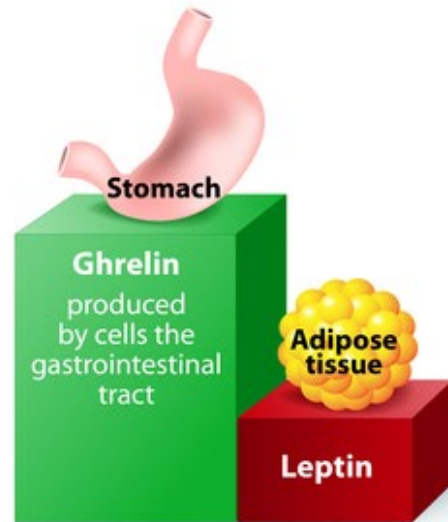
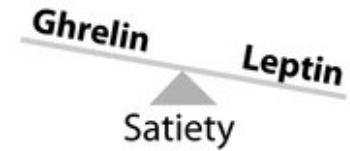
- Feeding difficulties can stem from low muscle tone and behavioral food refusal.
- Texture preference can drive food choices.





Contributions to Weight Gain

- Executive Dysfunction
- Hypotonia
- Feeding Difficulties
- High leptin levels



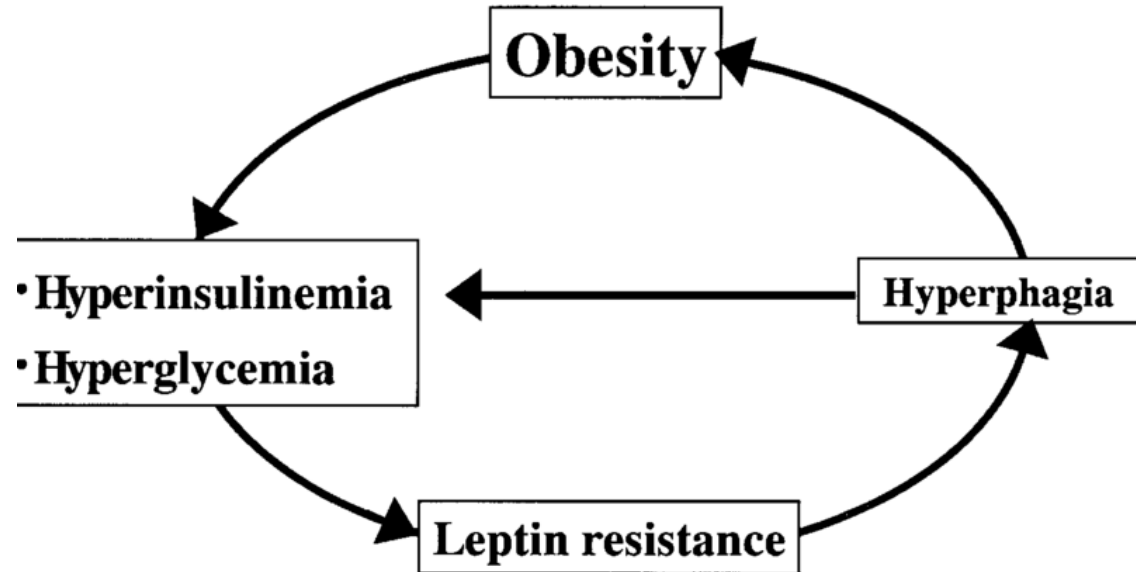
BEFORE EATING

AFTER EATING



Contributions to Weight Gain

- Executive Dysfunction
- Hypotonia
- Feeding Difficulties
- High leptin levels





Food Preferences and Texture



Image by azerbaijan_stockers on Freepik

Designed to be eaten in large amounts.
Easy to eat – Predictable – Salty / Sweet



Food Composition and Taste

Salty & Sweet



Image by vecstock on Freepik

Sweet vs Sweet:
Food Experiment!



Other issues that can impact nutrition:



- Malabsorption due to gastrointestinal malformations
- Constipation and/or reflux
- Endocrine dysfunction
- Seizures
- Autism

Medications

Abilify

Significant weight gain

Clozaril

Significant weight gain

Increased appetite

Dry mouth / reflux

Constipation

Diabetes / Hyperglycemia

Hyperlipidemia

Depakote

Increase appetite / weight

Nausea and vomiting

Decreased bone density

Tremor

Thyroid levels



Medications

Paxil

Increase appetite / weight

Changes in taste (decrease sweet and bitter thresholds)

May decrease serum sodium

Remeron

Significant weight gain and appetite increase

Increased drowsiness

Risperdal

Significant weight gain and appetite increase

Drowsiness

Increased prolactin -> bone loss / osteopenia

Elevated triglycerides





Medications



Lithium

Need consistent sodium intake

Fluid intake important

Increases thirst and weight

Monitor for diabetes insipidus and thyroid function

Ritalin / Concerta

Significant appetite decrease

Decreased growth with long term use

Seroquel

Significant weight gain and appetite increase

Diabetes

Hyperlipidemia



Medications

Lexapro

Increases appetite and weight

Dry mouth

Zyprexa

Significant appetite and weight increase

Diabetes

Elevated triglycerides

Increased prolactin

Zantac / Pepcid

Decrease Fe and B12 absorption

Take separate from Mg supplement

Nexium / Prevacid / Prilosec

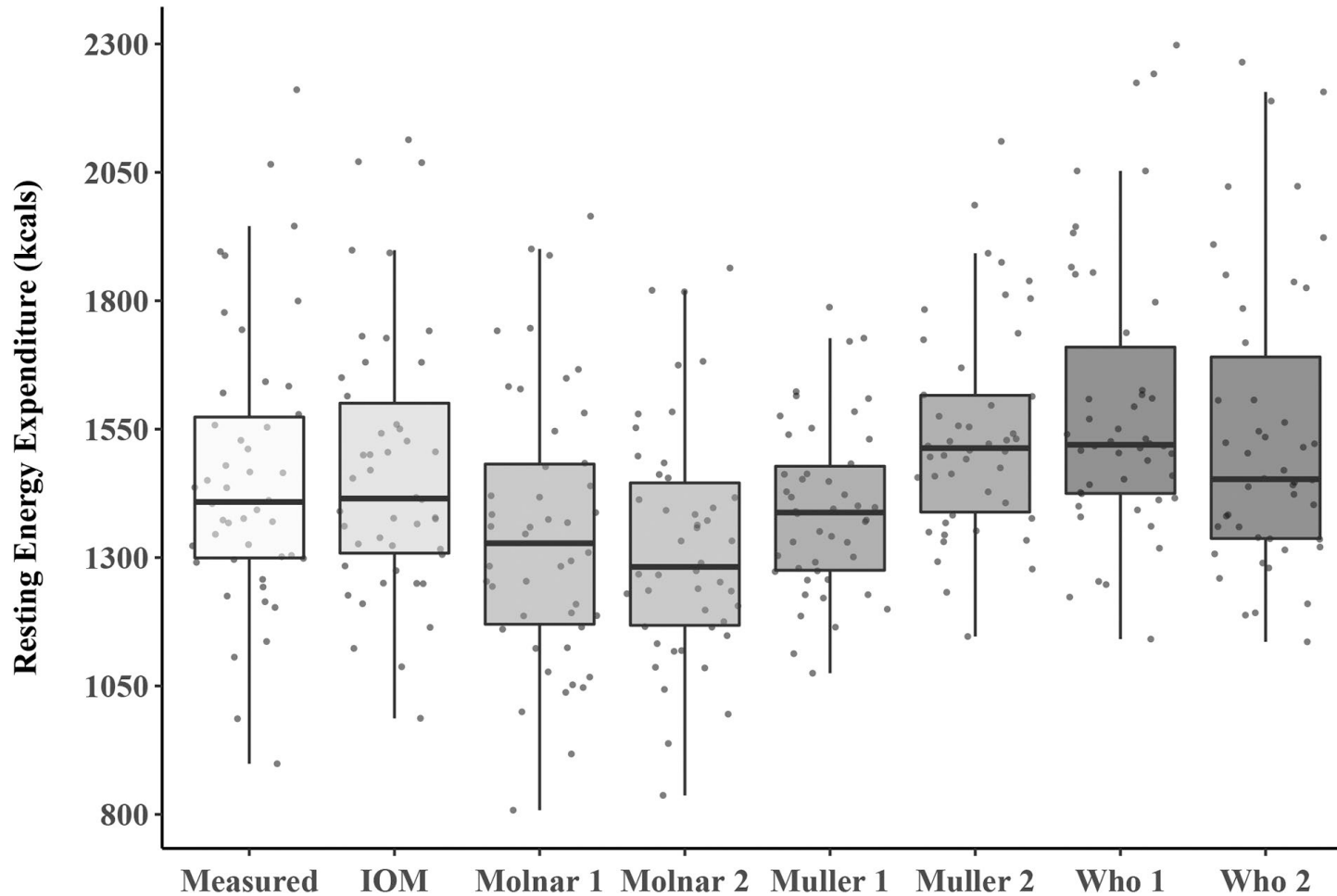
Decrease Fe B12 and Ca

Nexium lawsuit – CKD, dementia, bone fractures





Determining calorie needs



Helsel BC, et al. Resting energy expenditure in adolescents with Down syndrome: a comparison of commonly used predictive equations. *J Intellect Disabil Res.* 2023 Feb;67(2):112-122. doi: 10.1111/jir.12995. Epub 2022 Nov 24. PMID: 36423896; PMCID: PMC9839564.



Determining calorie needs

UNIVERSITY OF NEBRASKA MEDICAL CENTER™
MUNROE-MEYER INSTITUTE
 NEBRASKA'S HEALTH SCIENCE CENTER PEDIATRIC FEEDING DISORDERS PROGRAM

Food Record

- Record everything consumed: both food and liquids. Record condiments and any additional fat, sugar or salt added to foods or beverages.
- You can estimate the amount of consumed using either percentages or household measurements. Examples: 50% or 1 Tbsp
- Include all formulas and/or supplements. If mixing formula, include recipe. Example: 4 scoops Similac Advance + 4 oz water for a 9 oz bottle.

Further details:

- Preparation: in addition to what foods eaten, please record how the food was prepared: fresh, canned, pan fried, deep fried, baked, broiled etc. When possible, record any fat used in cooking.
- Brand and type: Be sure to record the brand of food/beverage and specifics such as frozen, canned, whole, 1%, etc.

Date	Food & Beverage	Brand	Amount Presented:	Amount Eaten:	Care-giver initials
4/13/2021	6 am bottle: 4 scoops + 4 oz water	Similac Advance	9 oz	7 ½ oz	
20 min	• Fruit Loops	Kellogg's	¼ cup	¾ cup	
Breakfast	• Whole milk	That's Smart	8 oz	8 oz	
30 min	• Chicken nuggets, baked	Tyson	5 each	3 each	
Lunch	• BBQ sauce	Great Value	1 tbs	1 tbs	
40 min	• Carrots (Canned)	Del Monte	½ cup	~50%	
	• Red Grapes		10 grapes	2 grapes	
Dinner	• Apple Cinnamon power blend	Gerber	4 oz tub	all	
45 min	• Homemade Mango Shake (1 cup mango, 1 cup milk)	Tap	2 cup	~75%	
9pm	• Tubefeeding: Pediasure		16 oz	all	
2.5 hrs			Rate: 200ml/hr	480 ml	

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 402.559.5740 / fax 402.559.5950 / unmc.edu/mmi



Common recommendations for weight loss



UNIVERSITY OF NEBRASKA MEDICAL CENTER[®]
MUNROE-MEYER INSTITUTE

NEBRASKA'S HEALTH SCIENCE CENTERS PEDIATRIC FEEDING GUIDANCE PROGRAM

Food Record

- Record everything consumed: both food and liquids. Record containers and any additional fat, sugar or salt added to foods or beverages.
- You can estimate the amount of consumed using either percentages or household measurements. Examples: 50% or 1 Tbsp.
- Include all formulas and/or supplements. If missing breaks, include recipe. Example: 4 scoops vanilla Advance + 4 oz water for a 9 oz base.

Further details:
 - Preparation: In addition to what foods eaten, please record how the food was prepared: fried, canned, stir-fried, deep fried, baked, broiled, etc. When possible, record any fat used in cooking.
 - Brand and type: Be sure to record the brand of food/beverage and specifics such as soup, canned, whole, 1% etc.

Category	Food & Beverage	Brand	Amount Presented	Amount Consumed
Breakfast	8 oz bottle + water + 4 oz water	Smith's Advance	7 1/2 oz	7 1/2 oz
	Fruit Loops	That's Smart	9 oz	8 oz
	Whole milk		8 oz	8 oz
Lunch	Chicken nuggets, baked	7 from	2 each	2 each
	480 sauce	Great Value	1 tsp	1 tsp
	Carrots (Canned)	Lot Monte	10 grapes	10 grapes
	Real Grapes		4 oz tub	all
Dinner	Apple Cinnamon power blend	Garbar	2 cup	all
	Homemade ketchup		14 oz	all
	water	Tap	480 ml	480 ml
Snack	Tubefeeding Pediflore			

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Image by gstudioimagen1 on Freepik

Photo by [Kenny Eliason](#) on [Unsplash](#)

Common recommendations for weight loss



UNIVERSITY OF NEBRASKA MEDICAL CENTER
MUNROE-MEYER INSTITUTE

NEBRASKA'S HEALTH SCIENCE CENTERS PEDIATRIC FEEDING DISORDERS PROGRAM

Food Record

- Record everything consumed: both food and liquids. Record contents and any additional fat, sugar or salt added to foods or beverages.
- You can estimate the amount of consumption using either percentages or household measurements. Examples: 50% of 1 cup, 1 slice.
- Include all formulas and/or supplements. If missing brands, include recipe. Example: 4 scoops vanilla Advance + 4 oz water for a 9 oz base.

Further details:

- Preparation: In addition to what foods eaten, please record how the food was prepared: broiled, canned, stir-fried, deep fried, baked, broiled, etc. When possible, record any fat used in cooking.
- Brand and type: Be sure to record the brand of food/beverage and specifics such as: soup, canned, whole, 1%, etc.

Category	Food & Beverage	Brand	Amount Presented	Amount Consumed
Breakfast	8 oz bottle 4 oz water + 4 oz water	Similac Advance	8 oz	7 1/2 oz
Breakfast	Fruit loops	Kellogg's That's Smart	1/2 cup	1/2 cup
Breakfast	Whole milk	7-iron	1/2 cup	1/2 cup
Lunch	Chicken nuggets, baked	Great Value	1 box	2 each
Lunch	4800 sauce	Lord Monte	10 grapes	1 box
Lunch	Carrots (canned)	Gerber	4 oz tub	all
Lunch	Real grapes		1/2 cup	1/2 cup
Dinner	Apple cinnamon power blend	Tap	14 oz	all
Dinner	Homemade spaghetti		480 ml	480 ml
Dinner	Shake (one scoop, 1 oz milk, water)		14 oz	14 oz
Snack	Tubefeeding Pediflore		480 ml	480 ml

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Image by [gstudioimagen1](#) on [Freepik](#) </>
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Should we restrict specific foods/ingredients?



Carbs?

Dairy?

Sugar?

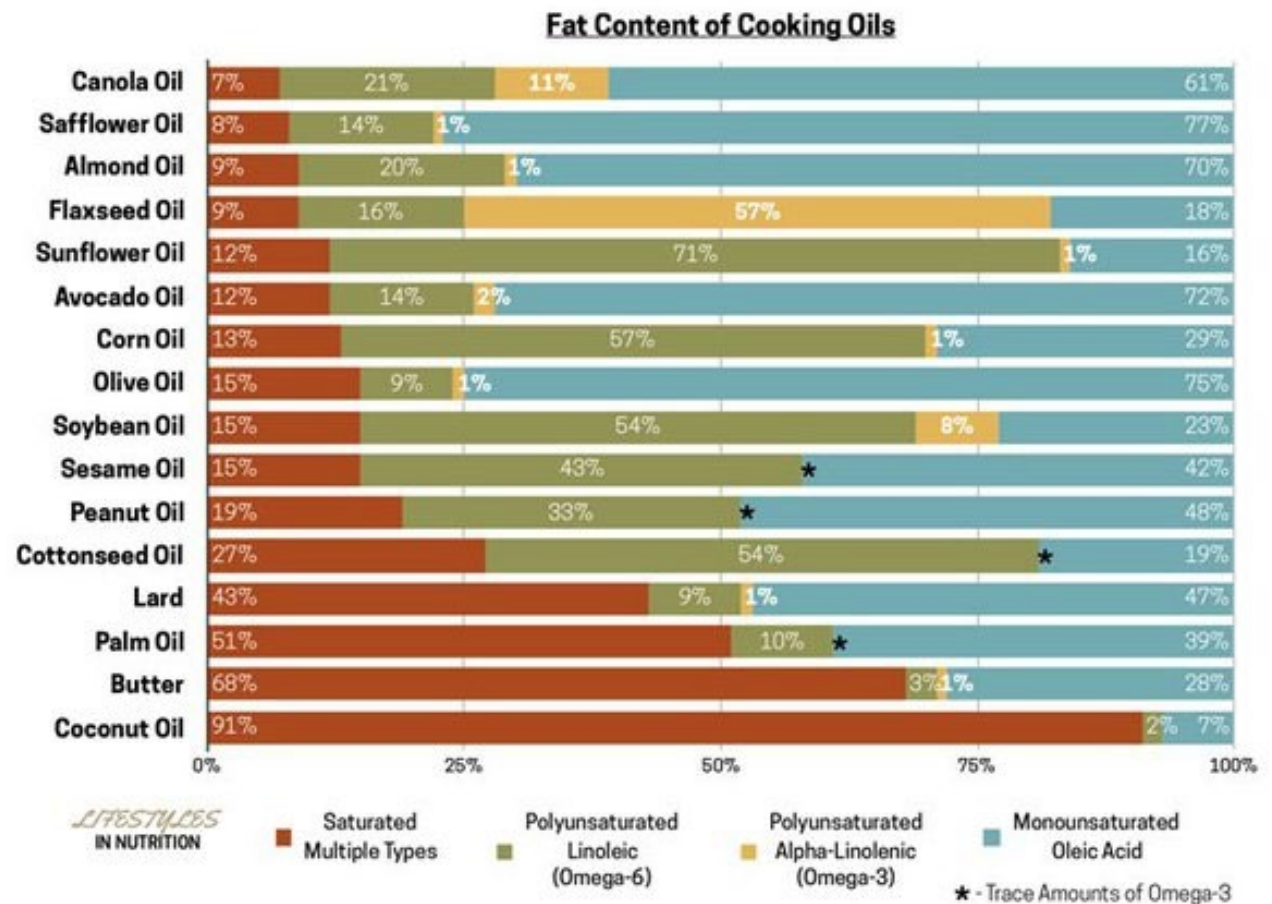
...oh my!





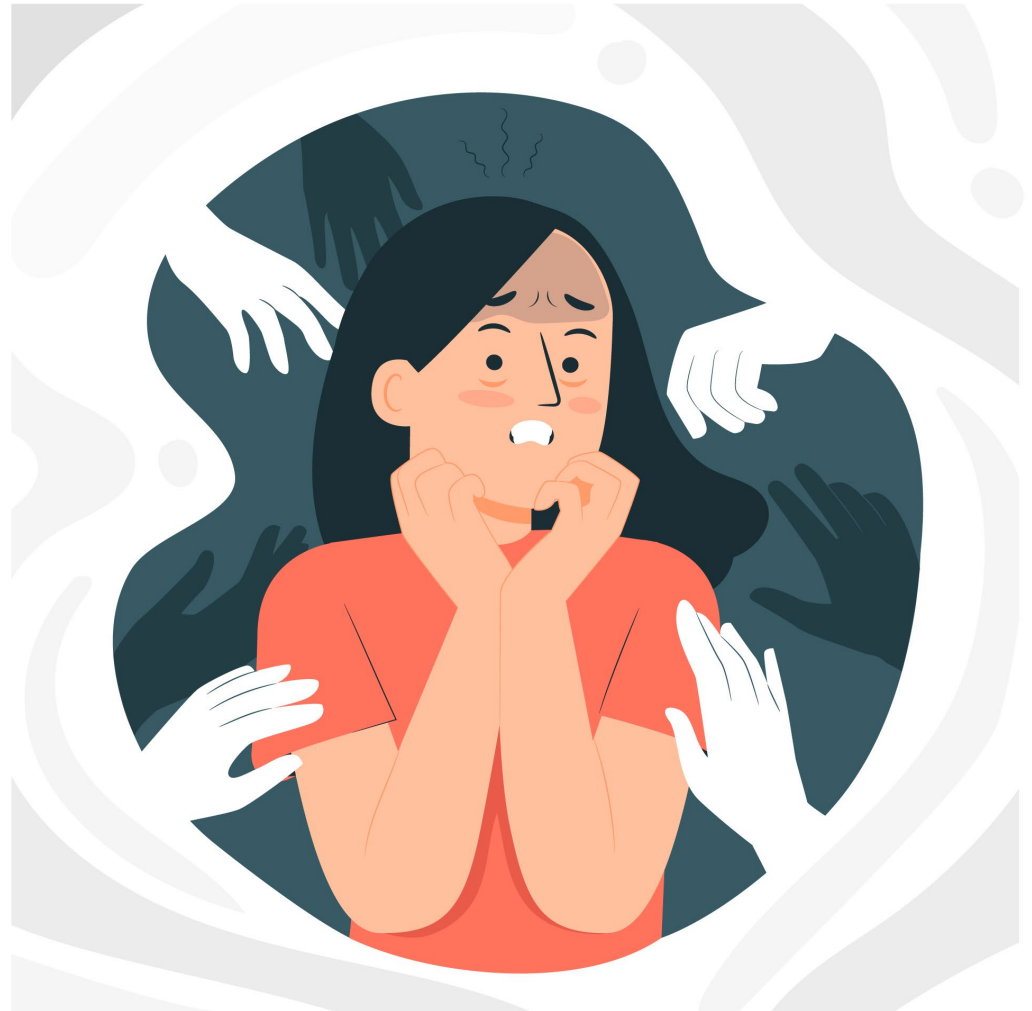
What about fat?

The BIG fat debate....



The stress of dieting

Psychological stress can also cause inflammation.



What does work?

What is realistic and specific to that individual?

Eating pattern for weight loss and reducing inflammation markers:

Mediterranean diet – start with a balance of high nutrient foods and preferred foods.

For sustainable results:
Need buy-in and time

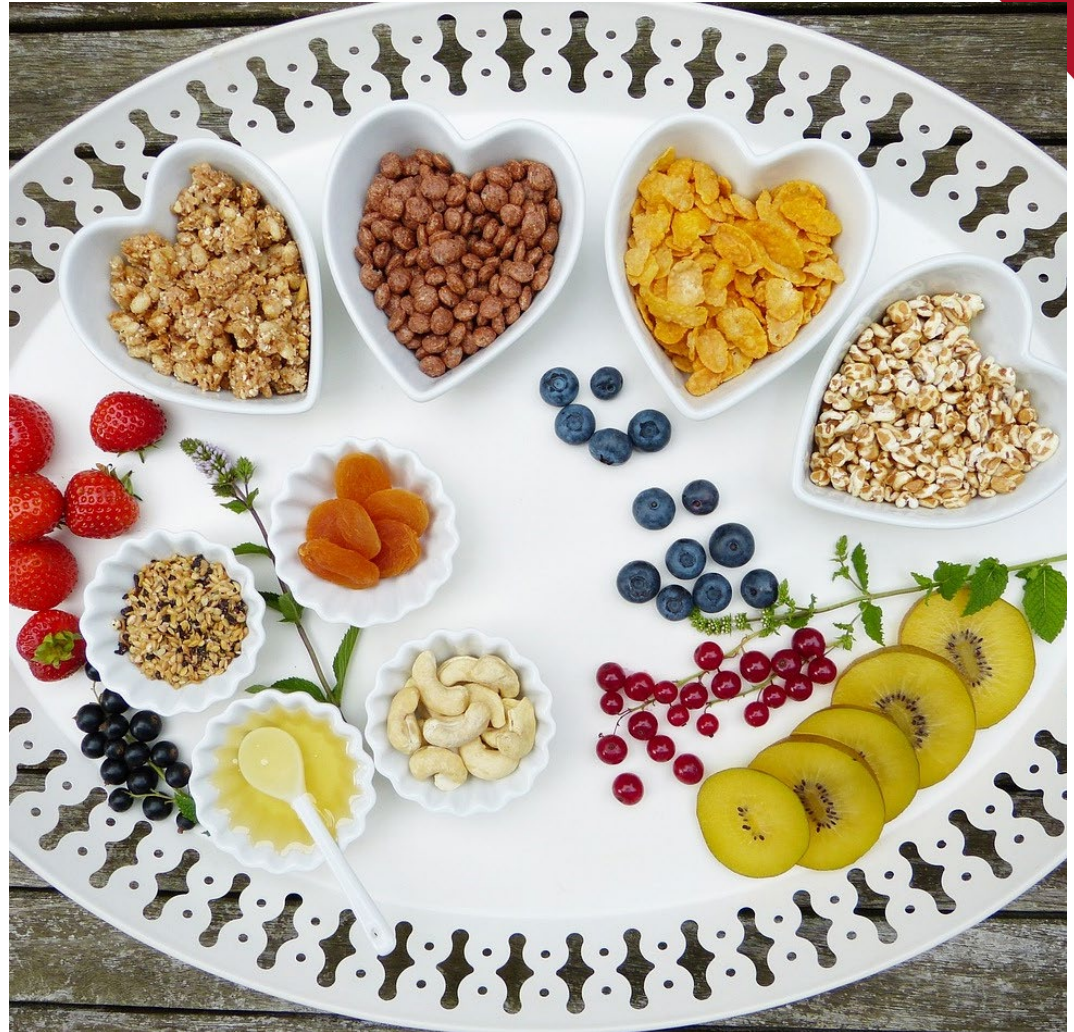


Image by timolina on Freepik

Diet Variety

A well-balanced diet with a wide variety of foods, especially whole foods and high fiber foods, nourishes a healthy gut microbiome.

Many weight loss programs will emphasize water, protein, fruits/veggies, and fiber





Mediterranean Diet Food Ideas

Soft proteins:

Tuna, salmon, sardines, ground chicken, eggs, natural peanut butter, protein drink.

Soft veggies:

Steamed or roasted vegetables, skin off, cut small. Turn vegetables into a sauce. Petite cut baby carrots, shredded lettuce salads with vinaigrette dressing or oil/vinegar.
Hearts of palm “pasta”

Soft fruits:

Canned fruits (not in syrup or pie filling)

Whole grains:

Popcorn, farro, oats, flaxseed



“Ease into it” Food ideas

Other easy to eat foods:

- ✓ Bone broth
- ✓ Peanut butter oat energy balls or mix peanut butter into oatmeal
- ✓ Ground beef in gravy
- ✓ Chopped chicken and chopped veggies with favorite condiment
- ✓ Freeze dried fruit
- ✓ Veggie tots





Amy's Maple Lime Salmon

- Fresh Atlantic Salmon filet
- Equal parts lime juice, real maple syrup, soy sauce, olive oil. Add grated fresh ginger.
- Marinate salmon in mixture for appx 30-60 min
- Cook salmon under High Broil until flaky (appx 7-8 min)
- Can use marinade as a sauce by bringing to a boil then simmer for 2-3 min






Do's and Don'ts

Do:

- Reduce the stress of eating / not eating
- Set clear expectations
- Start routines
- “Red yellow green” foods
- Find ways to keep “safe foods” in rotation
- Make trying new foods fun
- Allow for distractions when trying new foods

Don't:

- Go too strong with restrictions 
- Use other foods as rewards
- Take away all choices and options “You can't”
- Get angry or shame when diet isn't followed
- Provide unlimited access to snacks/grazing
- Give only hard-to-eat textures/tastes in one meal



Be an adventurous eater!

LIFE HACK: UPGRADE YOUR TASTEBUDS

How to be an
adventurous eater

#01

**ADULT TASTEBUDS ARE DIFFERENT
THAN KID TASTEBUDS!**

Try a food that you didn't like before. Your growing adult tastebuds might like it!

#02

TRY A NEW FOOD MORE THAN ONCE

Sometimes you need to taste a food at least 15 times before you can decide if you like it.

#03

TEMPERATURE MAKES A DIFFERENCE

Eat your hot foods first so they stay warm!
Cooked veggies that turn cold taste different.
Raw veggies will taste different than cooked.

#04

**ADD INGREDIENTS TO SOFTEN STRONG
FLAVORS**

Bitter foods (kale, brussel sprouts, arugula) - add sweet or sour like a lemon honey vinaigrette

Sour foods (tart apple, cranberry, lime) - add sweet or salty

#05

TRY PREPARING FOOD DIFFERENT WAYS

Cutting food smaller will also influence how food tastes. Veggies that are shredded or diced will allow more flavor from cooking or added dressing or fats.
examples: shredded salads or french cut green beans.

Roast (cook in an oven or air fryer) or pan fry instead of boiling.

#06

**BE CAREFUL OF EATING TOO MUCH
SUGAR OR SALT**

Eating too many salty or sweet foods can make it hard to taste other foods!

#07

MIX THE NEW FOOD WITH A FAVORITE FOOD

Try a fruit/veggie smoothie or add veggies to your pizza, mac n cheese, etc.



Trying new foods? Rate them!

Example descriptors of foods:

Bitter
Sweet
Salty
Citrusy
Earthy
Fresh
Fruity
Nutty
Savory
Tart

Buttery
Chewy
Creamy
Crunchy
Crispy
Tough
Delicate
Gooey
Sticky
Tender



Personalized Nutrition Therapy

An individualized dietitian session includes:

- Medication interaction
- Nutritional analysis
- Abilities and preferences





Medical Weight Loss Interventions

Bariatric Surgery

Vyvanse

Semaglutide

Mounjaro

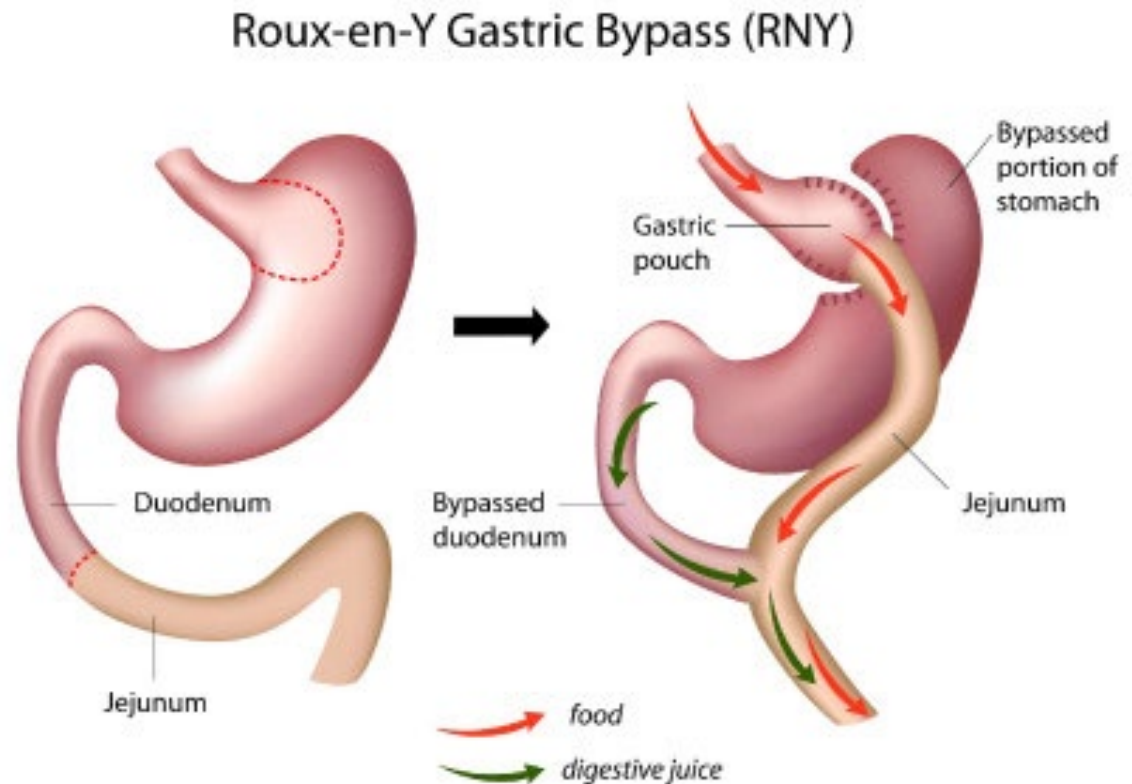


Photo courtesy of UI Health.



Bringing it all together:

- People with DS need less calories compared to those without DS although individual calorie needs will widely vary.
- High leptin levels possibly cause limited fullness cues making overeating easy to do.
- Limitations in executive functioning skills can create impulsivity and lack of understanding long term behavior consequences.
- Some processed food was created to be easy to eat and desirable.
- Changing taste preferences can be hard, but not impossible. Taste can be a learned behavior.
- Provide structure when starting a diet but do not place food in a hierarchy or “forbidden” if possible.
- Use caution when restricting food groups and weigh out the potential benefits with potential stressors and lifestyle.
- Children, from adolescent to adult, will often be more resistant to their parents’ input than others.
- Keep diet expectations realistic to help keep chronic stress low.



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