

THE
2ND DECADE



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Care and a Cure

DEBUNKING MYTHS AND EATING STRATEGIES

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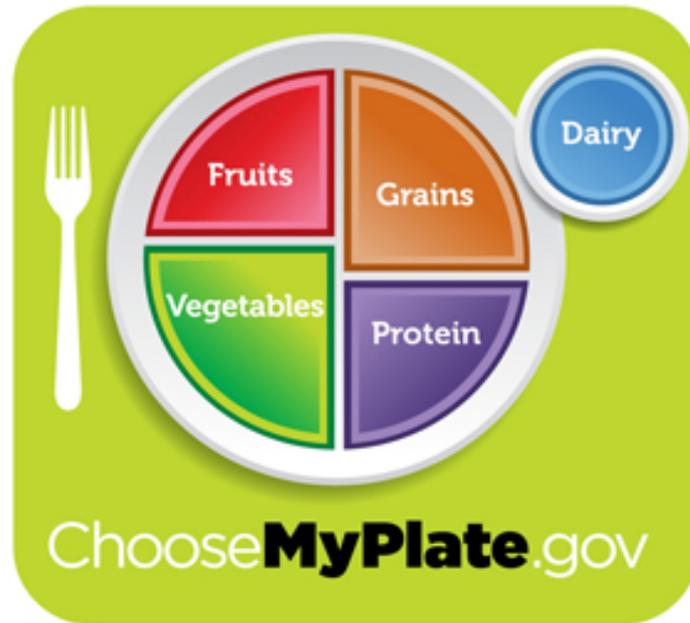
Disclosures

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- Medical Advisory Council-Cure SMA
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Outline

- General Healthy Nutrition Guidelines
- Debunking Myths and Nutrition Facts
- Eating Strategies
- Feeding Tubes
- Referrals
- Questions

General Healthy Nutrition Guidelines



Calories

- Calories provide energy
 - Sources of calories
 - Protein
 - Carbohydrates
 - Fat

Protein

- beans
- tender meat
- eggs
- seafood
- peas
- nuts
- seeds
- dairy, soy
- tofu



Carbohydrates

- ▣ Fruits

- fresh, frozen, canned, dried, diced, pureed, sliced, mashed

- ▣ Vegetables

- fresh, frozen, canned, raw, cooked, mashed, diced

- ▣ Grains

- Whole grains-whole wheat, corn, oats, quinoa, brown rice, rye, barley



Fats

- Healthy oils
 - ▣ Canola, olive, fish, nuts and seeds, avocado
- Limit saturated fats
 - ▣ Butter
 - ▣ Animal sources
- Avoid trans-fats
 - ▣ Shortening, margarine
- Limit bakery items and fried foods



How many calories?

- For a child-enough to grow,
- For an adult-enough to maintain

- Considerations-
 - ▣ Less mobile/less active-usually require less
 - ▣ More movement-may require more
 - ▣ Age-usually require less calories per lb body weight with age
 - ▣ Increased work of breathing-may require more
 - ▣ Decreased lean muscle mass-usually require less
 - ▣ Often use the plate method....with SMALLER plate...

FACT: Food can help constipation

- Constipation is a common problem
- Low/weak abdominal muscle tone
- Weaker movement through intestines
- Solutions:
 - Drink more fluids
 - Increase fiber intake (goal for kids: age +5 grams)
 - With ↑ fiber, make sure ↑ fluid
 - Add fiber slowly into diet



Constipation Solutions-FIBER

- ▣ Fiber containing foods:
- ▣ Oatmeal
- ▣ Fruits- Pear, apple, plums, raspberries
- ▣ Vegetables- broccoli, peas, baked potato with skin, spinach
- ▣ Whole grains-wheat, bran, quinoa, barley, brown rice
- ▣ Beans
- ▣ May need fiber supplement

Constipation Solutions

- ▣ Fruit juices such as prune, pear, apple (limit juice to 2-4 oz daily)
- ▣ Probiotics (live and active cultures)
 - Yogurt
 - Kefir
 - Drinks
 - Supplements
- ▣ Physical therapy exercises/positioning
- ▣ Bowel regulating medications may be needed



FOR ACUTE CONSTIPATION MEDICATION IS NECESSARY

FACT: Fiber causes diarrhea

FACT:

- Soluble fiber actually thickens stool
- Probiotics
- Avoid trigger foods
- In some cases medicines are needed
- For frequent diarrhea, may need electrolytes , zinc

~~FACT~~: Caffeine will cure sleepiness

FACT:

- Excessive caffeine intake can have side effects:
 - ▣ Fast heart rate
 - ▣ Muscle tremors
 - ▣ Upset stomach
 - ▣ May increase urination
- Poor nutrition can cause low energy
 - ▣ “You are what you eat.”
- DM related sleepiness is not improved by nutrition
 - ▣ Talk with MD about respiratory/medications.

FACT: Coconut milk is BEST

FACT:

- Contains oils that are better absorbed by the body
- Higher in calories and saturated fat
- Lower in protein and calcium
- Contains vitamins C, E, and B; minerals iron, magnesium, phosphorus, potassium
- Contains heart healthy fat as well
- Moderation is the key

FACT: Large meals increase REFLUX

- Symptoms:
 - Chest/upper abdomen pain
 - Spit up/Aspiration
 - Feeding refusal
 - Bad breath
- Solutions:
 - Positioning
 - Limit eating 1 hour before sleeping
 - Limit spicy foods, chocolate, mint, tomatoes
 - Smaller meals, more often
 - Antacids/other medications
 - Manage constipation
 - Surgical option

~~FACT~~: More PROTEIN=MORE Muscle

FACT:

- Protein is used to help maintain tissues and muscle
- Protein needed to repair muscle
- Adequate calories/protein prevent breakdown of muscle for calories
- Too much protein may increase calcium losses
- Divide protein containing foods throughout the day

FACT: People with DM may develop insulin resistance

- Insulin is a hormone that is the “key” to giving your cells sugar for energy
- Increased blood sugar levels
- Corticosteroids may add to the problem
- Overfat in relation to muscle
- Solutions:
 - Moderate exercise (Consult MD)
 - Balancing Nutrition intake
 - Limit added sugars
 - Medications

Which food has more SUGAR?

- GLAZED DONUT
 - 260 calories
 - 12 g sugar, 14 g fat, 6 g sat fat, 1 g fiber
- 12 oz COLA
 - 150 calories
 - 41 g sugar, 0 g fat, 0 g fiber



Which food has more fiber?

- Granola bar
- 95 calories, 1 g fiber, 6 g sugar, 2 g protein, 3 g fat



- Maple and brown sugar instant oatmeal
- 160 calories, 3 g fiber, 9 g sugar, 4 g protein, 2.5 g fat



- Whole grain breakfast bar
- 120 calories, 3 g fiber, 12 g sugar, 2 g protein, 3 g fat



Which food has more FAT?

- ❑ Spicy Chicken Caesar Salad
- ❑ 720 calories, 6 g fiber, 43 g protein, 43 g fat



- ❑ Single Hamburger with cheese
- ❑ 570 calories, 3 g fiber, 30 g protein, 34 g fat



EATING STRATEGIES

- Back to the plate...
- Variety of foods “rainbow of colors”.
- IF you want to know exactly how your eating measures up:
 - 3 day food record with analysis from dietitian.
 - Track yourself online at <https://www.supertracker.usda.gov>
 - Many Apps-including:
 - My Fitness Pal, Loselt!, MyNetDiary



Nutrition from Foods

- Poor intake of nutrients:
 - ▣ Food is the best way if possible.
 - Eat a variety of fruits and veggies, and all food groups
 - ▣ New research-synergies with nutrients, antioxidants, phytonutrients
- Poor intake of calories:
 - ▣ Powerpacking
 - Adding higher calorie foods to boost calories
 - Peanut butter, sauces, cheese, healthy oils, powdered milk, avocado
 - ▣ Concentrating formula
 - ▣ Supplemental drinks/shakes
 - ▣ Adding protein powder, or other calorie adding powders

Nutrition from Supplements

- Multivitamin and mineral
- If not eating fish 2x week, consider fish oil (check mercury)
- Vitamin D/calcium- as needed based on intake
- Use caution with supplements
- Supplements do not need to follow same guidelines as food/drugs.
 - Check for US Pharmacopia, ConsumerLab, NSF International Approvals
 - Office of Dietary Supplements
 - <https://ods.od.nih.gov/>
 - Talk with MD or Dietitian

Meal Tips for PARENTS

- Be a good example
- Eat as a family whenever possible
- Limit distractions
- Make one family meal, make adjustments as needed
- Have family involved with meal planning
- Have an easy standby- nutrition drink, cold cereal, pbj
- Keep mealtimes positive, without pressure to eat
- <http://www.ellynsatterinstitute.org/htf/howtofeed.php>

Mini-meals and snacks ON THE GO

Protein/Fat

- Tuna pouch
- Hard boiled egg
- Prepackaged nuts/seeds
- Nut butter
- Hummus
- Greek yogurt/milk

Complete Meals

- Nutrition drink/bar

Carbohydrate

- Whole grain pita bread/crackers
- Fruit (fresh, freezer packed, cups)
- Carrots
- Peapods
- Cereal

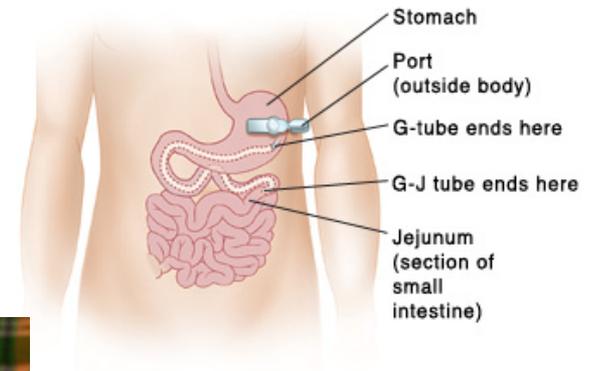
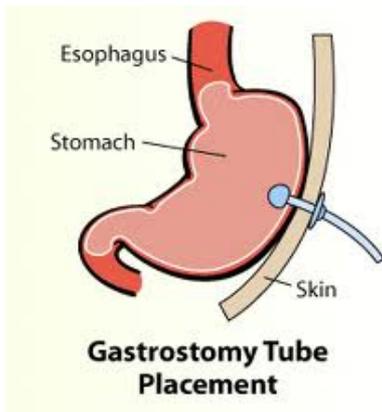
Feeding Difficulties

- Some people have trouble with hard to chew foods such as:
 - ▣ tough meats
 - ▣ sticky foods like peanut butter and thick cheese spread.
- Some people have trouble with thin, clear liquids.
- Try not to eliminate food groups. Think creatively and modify food and beverage textures and consistencies.
- Meal Fatigue and Feeling Full
 - ▣ Small meals more often can help
- Self-Feeding
 - ▣ Use adaptive utensils or plasticware
 - ▣ Offer finger foods
 - ▣ Straw cups or camelbacks

Examples of Modified Foods

Food Group	Level 3	Level 2	Level 1
Grains	Moistened bread, ckd/cold cereal, rice	Moistened pancakes, noodles, mashed potatoes	Pureed starches, breads
Fruits	Soft peeled fresh fruits, soft berries	Canned, cooked fruits-no skin, juice some pulp	Pureed fruits, juice, no chunks, smoothies
Vegetables	Cooked tender vegetables, shredded lettuce	Soft, well-cooked veg. chopped or diced, salsa	Pureed veg, tomato sauce, no chunks
Dairy	Milk, yogurt, cottage cheese, cheese	Milk, soft yogurt, cottage cheese	Milk, buttermilk, smooth yogurt
Protein	Thin sliced, ground, tender meat, eggs	Moistened ground/ckd meat, tuna, casserole, beans, scrambled eggs	Hummus, soft tofu with fluid, pureed meat
Desserts	Easy to chew, tender cakes and cookies	Pudding, soft fruit pies, moistened cakes, seedless jams	Smooth pudding, shakes, ice cream
Fats	Smooth creamy fats	Butter, oils, cream sauces & gravy, sour cream, whipped topping	Butter, oils, smooth sauces & gravy, sour cream, whipped topping

Feeding Tubes



When to Consider a Feeding Tube

- ❑ Failed swallow study
- ❑ Growth failure/losing weight
- ❑ Powerpacking is not working
- ❑ Issues with chewing/swallowing
- ❑ Fatigue with feeding
- ❑ Hydration concerns
- ❑ During illness
 - ❑ Inadequate intake for certain periods of time
- ❑ Consider before it becomes an emergency.
 - ❑ Parent/individual discussion
 - ❑ Under what circumstances??
 - ❑ Can schedule/plan somewhat in advance

Formula Types

- Standard/Soy
- Blenderized
- Hydrolyzed
- Elemental

- Formula type depends on individual tolerance/nutrition needs.
- In general, recommend starting with standard and working toward specialized as needed.
 - ▣ Insurance coverage varies
- Formula made to be nutritionally complete except in some cases...

Referrals to Professionals

- Speech language pathologist/Occupational Therapist
 - Assess for swallowing issues,
 - Improve oral motor skills, feeding therapy
 - Work on fine motor/hand skills
 - Alter texture of foods to decrease fatigue, thickeners, pureed foods,
 - Nipple flow/ bottle changes for bottle-fed infants
 - Positioning
 - Adaptive Equipment
- Dietitian
 - Consider evaluation every 1-2 years
 - Inadequate intake/nutrition concerns
 - Increased or poor growth
 - Considering feeding tube
 - If using a feeding tube, younger children every 3-6 months, older annually

Questions???
