Cystic Fibrosis Nutrition 101:
Getting Started

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Growth/Weight Assessment

Children/Adolescents
- Weight, length/height, and head circumference (if < 3 years old) measured at every clinic visit and plotted on the growth curve
- Early detection of weight/growth problems is important to prevent further decline.
- Birth to 2 years: **goal** weight/height ≥ 50 percentile.
- 2-20 yrs: **goal BMI ≥ 50th percentile**
- The graph showing correlation between BMI and FEV₁ for children is also helpful when educating patients and parents about BMI goals.
- Mid-parental height should be calculated and the range should be noted on the growth curve.

Adults
- Track weight history
- Record lifetime maximum weight on medical record
- Note weight loss or gain at each visit
- BMI goal of ≤ 22 for females and ≤ 23 for males.
- A graphic depicting various BMI values and the accompanying questionnaire are helpful when discussing weight gain goals.
- The graph showing correlation between BMI and FEV₁ for adults is also helpful when educating patients about BMI goals.

Energy and Macronutrient Guidelines

Energy and Protein
- Increased energy requirements secondary to malabsorption and in some cases increased basal metabolic rate.
- Calorie requirements are roughly 1.2 - 2 times the DRI for age
- Protein needs are roughly 1.5-2 times the DRI for age (generally easily met if meeting calorie goals)
- No perfect method for estimating calorie needs; the goal is sustained weight gain and growth in children and weight gain or maintenance in adults. Energy needs will be influenced by:
  - severity of lung disease,
  - degree of malabsorption
  - other factors (e.g. CF liver disease).
• **Other methods to calculate energy needs**

• **Tips for adding calories:**
  o Infants:
    - Increase caloric density of formula and/or expressed breast milk (concentrate to 24-26 calories/ounce; can add Polycose® to a concentration of 30 calories/oz)
    - Add butter/margarine to strained foods
    - Mix dry cereals w/formula or breast milk instead of water
    - Add cereal to vegetables and fruits
    - Instant breakfast powder to cereals, fruit/cereal mixtures
  o Children through adults
    - Butter or margarine on starches, sandwiches, vegetables, melted on top of cooked meats
    - Oil (esp. canola and olive) in soups, stews, drizzled on vegetables, used as a dip for bread/rolls
    - Nuts/peanuts on cereal, yogurt, ice cream, salads
    - Cheese on sandwiches, salads, vegetables, meat
    - Heavy cream in milk, mashed potatoes, gravy, milkshakes
    - Chocolate or strawberry syrup in milk, on ice cream, yogurt, waffles, pancakes
    - Thick sliced bacon on sandwiches, crushed on salads or cooked meats, as an accompaniment w/breakfast cereal

**Fat**

• High calorie, high fat (approximately 35-40 % of total calories) diet is recommended to meet increased calorie needs.

• Serum triene:tetraene ratio should be evaluated if essential fatty acid (EFAD) deficiency is suspected. Clinical signs are rare.
  o **Hyperlipidemia** is generally not a risk in CF; however it is a potential problem in pancreatic sufficient individuals. Pancreatic sufficient adults, and those with familial risk, should be screened according to national guidelines for the general population.
**Vitamins and Minerals**

**Vitamin Preparations**
- Increased need for fat soluble vitamins.
- Three companies make water miscible preparations of these vitamins.
  - Preparations also contain water soluble vitamins, and in some cases zinc.
  - Vitamins are available in a liquid, softgel, or chewable form.
  - When increasing the dose to 1 ml bid or 1 tab bid the dose should be divided to promote optimal absorption.
  - CFF *vitamin dosing guidelines*

**Monitoring Serum Vitamin levels**
- Vitamins A, D 25-OH, and E levels should be checked annually.
- Vitamin K status can be assessed indirectly by using prothrombin time.
  - Possible vitamin K deficiency if easy bruising, difficulty with blood clotting (e.g. hemoptysis or nose bleeds), even if prothrombin time (PT) is within normal limits
- Vitamin A is an acute phase reactant; level should not be measured if pt is acutely ill
  - Possible A deficiency if night blindness/difficulty seeing at night.

**High Vitamin A and E Levels**
Serum fat soluble vitamin levels may be elevated if:
- Vitamin was consumed just prior to the lab draw (recheck after a 12 hour fast, make sure patient does not take vitamins).
- Patient is post-transplant
- Patient has renal insufficiency
  - If fasting level is high, discontinue CF specific vitamins for 3 months (or indefinitely if post transplant or renal insufficiency) and replace with standard multivitamin.
  - If necessary add fat soluble vitamins (except the one that was elevated) per CFF *vitamin dosing guidelines*
  - Recheck serum level in 3 months.
Low Vitamin A and E Levels
- Assess adherence with prescribed vitamin supplements before recommending further supplementation
  - No specific guidelines, see CFF *vitamin dosing guidelines* for guidance in supplementing low levels
- Recheck low levels in 1-2 months after treatment is initiated

Vitamin K
- If prothrombin time (PT) is prolonged (elevated), supplement.
- Individuals with prolonged prothrombin time should be screened for CF related liver disease including physical exam and CBC to look for hypersplenism (low WBC, HGB and/or platelets), AST, ALT and GGT.
- No specific guidelines, but supplementation usually ranges from 2.5 – 10 mg given twice weekly to daily.
- Additional vitamin K may be required with CF liver disease and/or prolonged antibiotic use.

Vitamin D
See *vitamin D algorithms*

Sodium
- Risk for hyponatremia as a result of excess salt loss through sweat, especially in hot weather, fever, or extensive exercise/outdoor sports.
- High salt diet is recommended for all CF patients.
- Children and adults: add salt to foods and consume high salt foods.
- Infants with CF should get 2-4 mEq of sodium/day (1/8 – 1/4 teaspoon (total) of salt); can be added to formula

Zinc
- Total body zinc may be low due to malabsorption.
  - Particular problem in newly diagnosed patients that have not been treated for malabsorption.
  - Some infants with undiagnosed/untreated CF may present with acrodermatitis enteropathica, a severe rash in the diaper area and sometimes around the mouth, caused by zinc deficiency
  - Zinc deficiency symptoms include decreased appetite and growth; consider empiric supplementation since serum levels can be misleading.
Iron
- Iron deficiency can occur in individuals with CF.
- Serum ferritin may be falsely elevated in CF because it is an acute phase reactant.
- Monitor for anemia with an annual hemoglobin and hematocrit.

Malabsorption
- 85-90% of all individuals with CF are pancreatic insufficient (PI).
- Goal of enzyme therapy is to minimize symptoms of malabsorption, promote adequate weight gain and growth, and prevent deficiencies.
- Enzymes should not be reduced or discontinued to treat constipation or DIOS (distal intestinal obstruction syndrome).

Pancreatic Replacement Enzyme Dosing
- Each enzyme has a number associated with it; this is the USP units (U) of lipase, in thousands
  - For example, Creon 20 has 20,000 U of lipase per capsule
- To calculate the enzyme dose per kilogram per meal - divide the total U of lipase per meal by weight
  - Enzyme dose: Creon 10 3 capsules with meals
  - Weight: 15 kg
  - Creon 10,000 X 3 = 30,000 U lipase/meal
  - 30,000 divided by 15 kg = 2,000 U lipase/kg/meal
- Dosing
  - Infants: 1,000 U lipase/kg/meal or 2,000 – 4,000 U/120 ml formula or breast milk
  - Young Children: Start with 1,000 units lipase/kg/meal (half the dose for snacks), maximum dose is 2,500 units lipase /kg/meal or 10,000 lipase units/kg/day
  - Older Children and Adults: Start with 500 units lipase/kg/meal, maximum dose is 2,500 units lipase/kg/meal or 10,000 units lipase/kg/day, though it is rare for adults to need this high a dose
  - Can start with any brand name enzyme; providing samples of a product is very helpful as it will take most local pharmacies a couple days to order product.
  - Based on grams of fat ingested: 500-4,000 U lipase/gram of fat ingested (mean of 1,800 U lipase/g fat ingested).
- method is too cumbersome for many families.

**Enzyme administration guidelines**
- Enzyme capsules should be swallowed whole or beads mixed in a small amount of an acidic food (e.g. applesauce) which doesn’t require chewing.
- Patient should take another dose (or partial dose) of enzymes if eating again and it has been longer than 45-60 minutes since taking last enzyme dose.
- Enzyme capsules are given **before and/or during** all meals and snacks, **including milk and supplements**
  - Changing timing of enzymes to mid-meal may improve absorption
  - Simple sugars, such as popsicles, fruit juice, and fruit snacks, do not need enzymes unless consumed in large quantities
    - They are generally low in calories and regular consumption should be discouraged
- **Generic enzymes** should not be used because they may not dissolve the same as proprietary enzymes; pharmacists should not substitute one brand of enzymes for another without prior approval from prescriber
- Maximum dose is 2,500 U lipase/kg/meal or 10,000 U lipase/kg/day.
  - Fibrosing colonopathy is associated with exposure to prolonged high doses of pancreatic enzymes
- Enzymes should be stored at room temperature (not in the car or refrigerator)
- If pt is symptomatic and dose is at maximum safe limit: Consider switching enzyme brand
  - Acid blockers such as H2 antagonists or proton pump inhibitors (PPI) can improve enzyme efficacy
  - Spend some time asking about non-adherence
  - Take a diet history to see if the pt is drinking excessive amounts of juice if the pt has loose stools and a poor appetite
  - Recommend establishing a relationship with a gastroenterologist at your institution who is interested in working with CF patients
  - Ask the doctors to get an abdominal x-ray to look for constipation if the patient is gassy, has a poor appetite, or complains of stomach aches
• Educate patients and families to take an extra enzyme for large, high fat meals and snacks

**Brands of Enzymes**

• *Generic enzymes* may not dissolve well enough to treat CF pancreatic insufficiency, however many pharmacists are unaware of this problem.
• After April 2008, all enzymes on the market will be safe and effective based on new FDA guidelines.
• Ultrase, Creon, Pancrease and Pancrecarb (bicarbonate buffered) are name brand enzymes that are safe to use.
• It is important to write “DAW” (dispense as written) on enzyme prescriptions, or request “DAW” if the script is called to a pharmacy.

**Assessing Absorption**

• Fecal elastase can be used to determine if pt is pancreatic sufficient vs. insufficient.
• Quantitative analysis of absorption: 72 hour fecal fat.
• Possible signs/symptoms of malabsorption:
  - Stools: frequent (≥ 3/day), foul/strong smelling, bulky, light/pale color, oily appearance, fall apart easily in toilet, and/or difficult to flush.
  - Increased gas or frequent stomach aches.
  - The above symptoms are sometimes transient and may occur up to 12-24 hrs after consuming a high fat meal or missing an enzyme dose.
• Adjust enzyme replacement therapy only if symptoms persist longer than a few days and do not appear to be due to gastroenteritis.
• Other GI causes such as constipation or small intestinal bacterial overgrowth should be considered as well.
• Suboptimal weight gain and/or growth despite adequate caloric intake (no weight gain for 2 consecutive visits or any unexplained weight loss).
**CF Related Diabetes**

- Shares some characteristics of both type 1 and type 2 diabetes: insulin deficiency and insulin resistance.
- Insulin resistance is seen during times of stress, during pregnancy, and/or when on steroids.
- Insulin is an anabolic hormone, and insulin deficiency leads to unintentional loss of lean body mass, adipose tissue, and malnutrition.
- About 43% of CF patients over 30 years of age have CFRD (when screened annually w/OGTT).
- CFRD is most commonly diagnosed after the age of 18, but can occur at any age.
- OGTT is gold standard for diagnosing CFRD.
- Pts can develop CFRD without any symptoms, therefore annual screening is important.
- CFRD patients are at risk for the development of microvascular disease: retinopathy, neuropathy, and nephropathy.
- They are not at risk for macrovascular (cardiovascular) disease.
- Ketoacidosis is rare, even with consistently elevated blood glucose levels.
- CFRD may be transient, e.g. only during an acute illness or while using steroids.

**Treatment**

- Goal is to achieve and maintain good nutritional status and normalize blood sugars.
- **Insulin** is treatment of choice for any patient with fasting hyperglycemia, or those without fasting hyperglycemia if risk factors are present (e.g. declining weight and/or lung function).
- Continue usual high-calorie, high-fat, and high-sodium diet; counsel family to ignore the usual dietary advice for people with diabetes.
- Short acting insulin is usually prescribed to cover carbohydrates consumed at meals and snacks.
- Long acting insulin is necessary if pt has fasting hyperglycemia.
- Spread carbohydrate intake throughout the day if not being treated with insulin to prevent high blood glucose after meals.
- Restrict high-carbohydrate beverages between meals to control blood glucose.
**Nutrition Education for CFRD**
- RD should be knowledgeable about the special nutrition needs of patients with CF.
- Communication between the CF dietitian and the endocrine dietitian is critical to make sure the CF nutritional requirements are understood and to minimize confusion for the patient.
- Ideally, patients should be followed by an endocrine team; endocrinologist, nurse and dietitian certified diabetes educators who are familiar with CFRD.
- *Managing CF Related Diabetes* is a free reference guide available for patients and families (copies can be obtained by contacting the CF Foundation).
- Patients and families should be told that most cookbooks and websites for diabetes will give incorrect advice for those with CFRD.

**CFRD and Pregnancy**
- Dietary restriction is not recommended as a way to control blood glucose during pregnancy.
- If CFRD is present, recommend strict blood glucose control for several months prior to conception.
- Insulin needs double or triple as the pregnancy progresses, so blood glucose should be closely monitored to make appropriate insulin adjustments.
- Women with CF are at high risk of developing gestational diabetes.
- Oral glucose tolerance test should be preformed before pregnancy or once the pregnancy is confirmed, and should be repeated in the second and third trimesters, or if weight gain is inadequate.

**CF Osteopenia/Osteoporosis**
- Osteopenia and osteoporosis are more prevalent in patients with CF, especially as they get older.
- Risk factors:
  - Low body weight
  - Vitamin D deficiency
  - Delayed puberty
  - Chronic infection
  - Diabetes
  - Inactivity
  - Chronic use of corticosteroids
• If one or more risk factor is present a dual x-ray absorptiometry test (DXA) is recommended.
• For those without additional risk factors obtain DXA annually or every other year (if previous DXA is normal) beginning at 18 years.
• Individuals with osteopenia/osteoporosis should have annual serum calcium, phosphorus, intact parathyroid hormone and 25 OH-vitamin D monitored.
• *Nutrition: Bone Health and CF* is a booklet that discusses CF bone disease.

**Nutritional Supplements**

- Few high calorie supplements have been designed specifically for the CF population.
- Any high calorie food or beverage can be beneficial if used to supplement calories at meals/snacks rather than replace them.
- Studies looking at the impact of oral supplements on overall caloric intake and weight gain have not consistently shown that the supplements are beneficial.
- Patients frequently become burned-out on oral supplements

**Tube Feedings**

- Considered when a patient is not achieving adequate weight gain after absorption and oral intake have been maximized.
  - Discuss as a team at what point this is reached
- It usually takes multiple discussions and time for patients and families before they will agree to tube feedings
- *Supporting Nutrition – Understanding Tube Feeding*, is an educational booklet for patients and families. Order through your DCI rep, or online at www.cff.org.
- Gastrostomy tube placement is usually chosen over nasogastric tube feeds due to the chronic nature of the illness
- Significant sinus disease can interfere with or become worse with NG feeds
- Once the decision to get a tube has been made, refer to either a gastroenterologist or a surgeon, depending on the facility and the existing co-morbidities.
• The presence of reflux may influence the type of surgery or feeding tube (e.g. GT vs. JT) that is placed. Patients usually need an upper GI and/or pH probe prior to tube placement, especially if reflux is suspected.
• Initial feeding goal after the tube has been placed is ~50% of needs over 8-10 hours while patient sleeps
• Intact formulas can be used in conjunction with enzymes. Higher caloric density formulas (1.5 or 2 calories/cc) allow for high calories in a smaller volume.
• Semi-elemental formulas can be used for patients with significant GI symptoms; may be better tolerated if pt has severe lung disease
• There is not any good data on the best way to give enzymes with tube feedings. A meal dose of enzymes is usually given at the beginning and end of the feeds (ideally we would give mid-cycle but then no one would sleep!)
• Some centers use powdered enzymes which are mixed into the formula
• Feeding schedules should be based on individual patient and family needs, and can be adjusted in clinic.
• Monitor for hyperglycemia by checking a blood sugar 2 hrs into tube feeding; insulin therapy should be initiated if ≥ 180 mg/dl

**Nutrition Programs**
The CF community has a variety of programs to provide free and reduced cost vitamins, nutritional supplements, and other products.

**Pregnancy and Lactation**

*Pre-pregnancy Assessment*
• Optimum for patient to meet with the RD when contemplating pregnancy in an effort to maximize nutrition prior to the pregnancy.
• BMI goals should be established and nutrition history should be reviewed.

**Vitamins and Minerals**
• Vitamin A (retinol) intakes above 8,000 IU per day can be teratogenic.
• Serum vitamin A status should be monitored to maintain levels within the normal range.
• All pregnant women should receive at least 400 micrograms of folic acid every day.
• The combination of one CF specific vitamin and one prenatal vitamin should meet vitamin and mineral needs.

**Weight Gain Goals**
• Pre-pregnancy weight determines the weight gain goals during pregnancy.
• Standard *prenatal weight gain charts* can help determine reasonable goals.
• Additional calorie needs will vary based on pre-pregnancy weight, degree of malabsorption, pulmonary status and presence of infections.

**Gestational Diabetes**
See CFRD section for additional information.

**Breastfeeding**
• Acceptable as long as the mother can consume adequate calories to maintain an acceptable weight
• Calorie needs increase by approximately 500 calories per day during lactation.
• Breast milk content is not significantly different compared to someone without CF
• Adequate fluids are also important for adequate milk supply and should be encouraged.
• A calcium supplement should be given if intake is inadequate

**Transplant**
• Since the early 1980’s, lung transplantation has been pursued as an option to improve quality of life for many persons with end-stage CF.
• Malnutrition may adversely affect transplant outcomes and the dietitian serves an integral part of the transplant team.

**Pre-Transplant Nutrition**
• Patients are typically malnourished as a result of chronic disease.
• Nutrition assessment criteria are the same as outlined by the CFF.
• Calorie needs are often significantly higher due to increased work of breathing and lung infections.
• Gastroesophageal reflux and abdominal pain are very common and can lead to decreased appetite.
• Frequent high calorie meals, snacks and beverages and often gastrostomy tube feedings are used to help maximize caloric intake
• Goals for targeted weight gain and BMI should be set between clinic visits and should be reasonable (base on starting weight rather than BMI goals for general CF population)

Post-Transplant Nutrition
• Goals are to prevent weight loss and infection, promote healing, and minimize gastrointestinal complications while avoiding drug-nutrient interaction.
• Nausea and anorexia are common side effects immediately after transplant.
• Initially, calorie needs are elevated due to the body’s effort to promote healing and fight infection.
• Patients with pancreatic insufficiency should continue their same enzyme regimen and stools should be monitored closely.
• DIOS can occur due to slowed motility from pain medications and decreased activity.
• CFRD can occur due to use of prednisone
• Previous vitamin and mineral regimens should be restarted and blood levels monitored regularly for adjustments.
• Low magnesium levels are common when taking immunospressive medications and supplementation may be necessary.
• Patients still have CF pancreatic disease and need to be monitored at a CF Center

Medications Post-Transplant
• Medications are prescribed to suppress the immune system in order to prevent rejection of the transplanted organs.
  o Primary immunosuppressive medications include: Tacrolimus (Prograf®), Prednisone, Cyclosporin (Neoral®), Mycophenolate (Cellcept®), Rapamycin (Rapamune®) and Azathioprine (Imuran®).
  o It is recommended for patients to take these medications on a consistent basis either fasting or after a meal.
  o Medication levels are measured in the blood and changes in medication doses are determined from the levels.
Other medications including antacids, antibiotics, antifungals and grapefruit juice can alter the drug levels of the immunosuppressants.

- Vomiting or diarrhea may also affect drug levels
- Renal function must be closely monitored when using Tacrolimus or Cyclosporin, since impairment of renal function can occur with long-term use of these medications.
- Adequate amounts of fluids should be encouraged, especially during hot weather.

**Complications Post-Transplant**

**Bone Disease**
- Recommendations for managing CF bone disease post-transplant include maintaining a normal weight, supplementing with calcium and vitamin D, encouraging exercise, and using bisphosphonates when necessary.
- Transplant recipients should have an annual DXA scan

**Diabetes**
- CFRD is common in CF individuals awaiting transplant.
- Education and treatment of CFRD is critical pre-transplant to aid in their medical management post-transplant.
- High doses of steroids may be needed to treat rejection and can cause temporary diabetes. In many cases, this resolves when the steroid dose is lowered.

**Food Safety**
- Post transplant patient is at higher risk of food borne illness due to their immunosuppressed state.
- Transplant patients should not eat raw or undercooked eggs, meat, poultry and fish, and unpasteurized milk products.
- Symptoms of a food borne illness include nausea, vomiting, abdominal cramps, diarrhea, body aches and pains, fatigue and fever.
Problematic Eating Behaviors in Toddlers/Children

- More common in CF families due to added pressure to get child to gain weight, and more attention on eating
- *Assess for eating behavior problems* in all toddlers and children with CF, even if they are growing well
- Common issues faced by parents of children w/CF
  - Distractions at mealtimes (more time playing or talking instead of eating)
  - Longer time to finish meals/slow eating
  - Wants parent to be short order cook, requesting different entrees than what is being served
  - Picky eating, esp. high calorie foods/additives and sometimes enzymes
  - Family stress at meals due to child’s eating behaviors

- Preventing problematic eating behaviors
  - Structured meal and snack times (NO grazing)
  - Avoid distractions at meals (e.g. toys, television)
  - Teach parents to praise children when they are eating well; ignore them when they are not eating
  - Reward for eating well and behaving at meals
  - Discourage coaxing or begging child to eat
  - Limit length of meals to 20 minutes; do not allow more food or beverages until next scheduled snack or meal
  - Offer children options on how to add calories to food and/or which strained fruit for administering enzyme beads to provide them with choices
  - Make foods and beverages calorically dense before serving
  - Keep introducing new foods, even if the child refused the food in the past

Additional Educational Resources
The following resources are designed to help with patient education. The nutrition education folder on Port CF has a wide variety of education materials.

- Nutrition Education folder on Port CF
- Salt and Cystic Fibrosis
- CF cookbooks
Clinical/Quality Improvement Resources

The following resources are examples of materials that have been developed by RDs/CF teams at a variety of centers. They are meant to help with the implementation and design of center specific information.

- Methods to assess nutrition risk/screening
- Treatment/intervention algorithms
- Target nutrition action plan
- CF Nutrition action plans
- CF nutrition flow sheet
- Diabetes self care log
- Nutrition evaluation for CF patients
- Adult nutrition assessment
- Adult CF nutrition questionnaire
References


   PORT CF -
   https://www.portcf.org/educationalmaterials.asp?folder=%2FResources%2FConsensus+%26+Guidelines%2FComplications+of+CF


   PORT CF -
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