

Nutrition and Wound Healing in EB: The Role of Diet and Vitamin C

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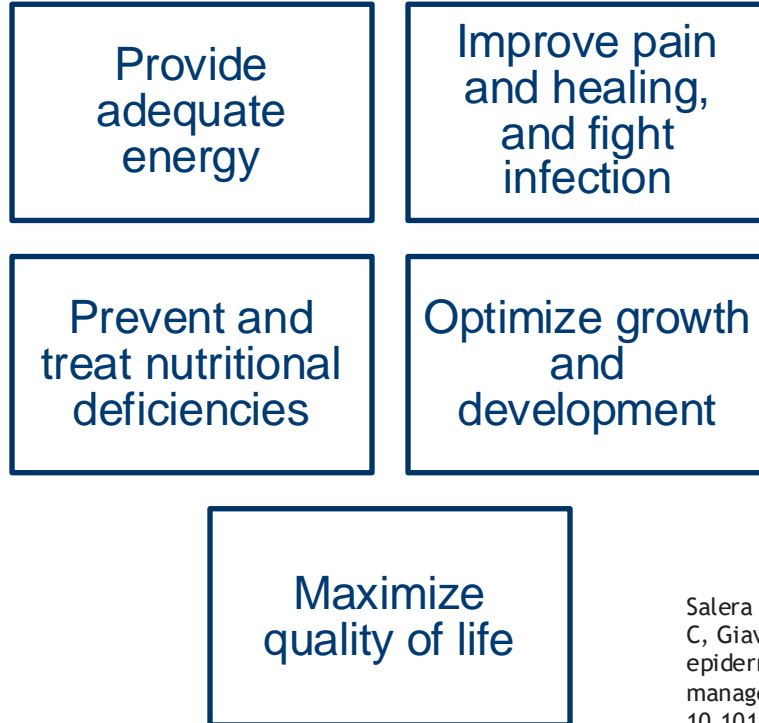
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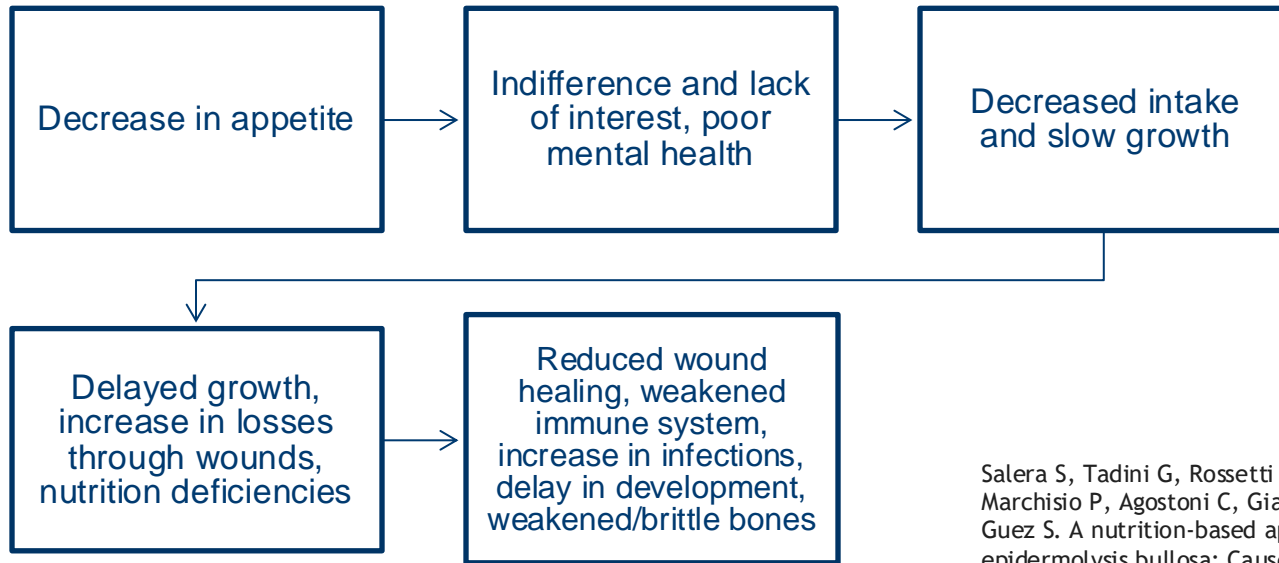
Good Nutrition in EB is Essential to



Salera S, Tadini G, Rossetti D, Grassi FS, Marchisio P, Agostoni C, Giavoli C, Rodari G, Guez S. A nutrition-based approach to epidermolysis bullosa: Causes, assessments, requirements and management. *Clin Nutr.* 2020 Feb;39(2):343-352. doi: 10.1016/j.clnu.2019.02.023. Epub 2019 Feb 21. PMID: 30857908.



Cycle of Poor Intake/Nutrition and EB



Salera S, Tadini G, Rossetti D, Grassi FS, Marchisio P, Agostoni C, Giavoli C, Rodari G, Guez S. A nutrition-based approach to epidermolysis bullosa: Causes, assessments, requirements and management. Clin Nutr. 2020 Feb;39(2):343-352. doi: 10.1016/j.clnu.2019.02.023. Epub 2019 Feb 21. PMID: 30857908.



How EB Symptoms Affect Nutritional Status

- Decreases Intake
 - Mouth blisters
 - Scarring and decrease in mouth size
 - Dental problems
 - Reflux
 - Strictures and trouble swallowing
 - Constipation
 - Mobility and problems with hands
 - Pain
 - Depression
- Increases Needs
 - Low absorption of nutrients
 - Increased losses through the skin
 - Infections

Salera S, Tadini G, Rossetti D, Grassi FS, Marchisio P, Agostoni C, Giavoli C, Rodari G, Guez S. A nutrition-based approach to epidermolysis bullosa: Causes, assessments, requirements and management. *Clin Nutr.* 2020 Feb;39(2):343-352. doi: 10.1016/j.clnu.2019.02.023. Epub 2019 Feb 21. PMID: 30857908.



Nutrition Needs

Are high due to

Blister and open wounds with nutrient losses along with infection

The need for catch up growth



Nutrition Needs

Calories: 100-150% of estimated needs for age or more

Protein: 115-200% of estimated needs for age or more

Fluids: 100% of estimated needs for age or more



Age Groups



Infants



- Fortified breast milk and/or infant formula is usually necessary
- A Haberman nipple or Special Needs feeder may be helpful
- Solids can be introduced at 6 months
- High calorie purees: avocado, banana, sweet potato, peas, chicken/turkey/beef
- High calorie additions to purees/soft solids: avocado, sour cream, hummus, mashed beans/lentils, whole milk yogurt, nut and seed butters/powders, and oil



Children, Teens, and Adults

- Meals by mouth as able
- High calorie foods/additions
- Use high calorie oral nutrition supplements as needed
- Adaptive tools to maintain independence at mealtimes
- Tube feeding may be helpful



High Calorie Additions/Meals

- Proteins and Meats
 - Eggs or egg salad
 - Hummus or other bean dips
 - Deli meats
 - Canned fish
 - Chicken salad
- Fruits and Vegetables
 - Sweet potato
 - Peas
 - Avocado
 - Banana
- Dairy
 - Cheese
 - Heavy whipping cream
 - Whole milk yogurt
 - Cottage cheese
 - Sour cream
 - Whole milk
- Grains
 - Oatmeal
 - Quinoa and rice
 - Pancakes and Waffles
 - Wheat Germ and ground flax
- Fats and Sweeteners
 - Oils
 - Butter
 - Maple syrup and honey
 - Canned coconut milk
 - Salad dressings



Oral Supplements and Tube Feeding



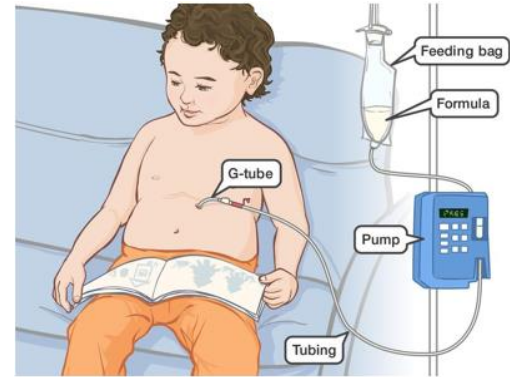
Oral Supplements

- Help meet nutrition needs by mouth when intake does not meet needs
- Provides extra calories, protein, and vitamin and minerals
- Variety of options including with or without fiber, high calorie, added fruits and vegetables



Tube Feedings

- Most often a gastrostomy or G-tube is placed
- Helpful when oral intake is low and not meeting nutrition needs
- Still provides opportunity to eat by mouth
- Usually well tolerated and can help improve growth, development, and quality of life
- Feeds can be given during the day or overnight
- Delivery options: by pump, syringe, or gravity

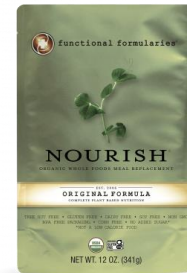


Zidorio APC, Dutra ES, Castro LCG, Carvalho KMB. Effectiveness of gastrostomy for improving nutritional status and quality of life in patients with epidermolysis bullosa: a systematic review. *Br J Dermatol.* 2018 Jul;179(1):42-49. doi: 10.1111/bjd.16139. Epub 2018 Apr 17. PMID: 29168183.



Tube Feeding Formula Options

- Variety of tube feeding formulas available
- Blenderized or whole food formulas are now also available
- If standard formulas are not well tolerated, there are formulas with partially broken down proteins available that are more easily digested and well tolerated



Labs and Vitamins and Minerals



Labs

- Comprehensive Metabolic Panel
- Complete Blood Count
- Iron Panel
- Vitamin D
- Zinc
- Carnitine
- Selenium
- Vitamin C
- Vitamin A (if there are eye concerns)



Vitamins and Minerals

- Multivitamin
- Iron (to treat anemia)
- Zinc (to help improve wound healing and appetite)
- Vitamin D (to improve bone health)
- Selenium and Carnitine (to protect the heart)
- Vitamin C

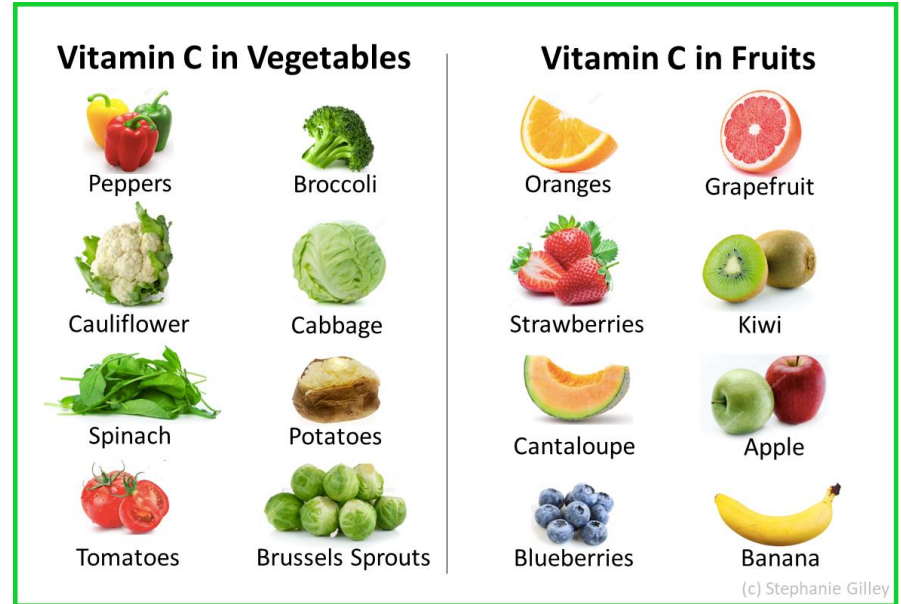


Deeper Dive into Vitamin C



Vitamin C Background

- Vitamin C is essential for growth and repair of all tissues
- Vitamin C helps make collagen in the skin
- Plays a role in wound healing
- Helps protect cells and strengthen the immune system



Vitamin C and EB

- Vitamin C needs are higher
- Cooking food very soft or into purees decreases the amount of vitamin C in foods
- Vitamin C deficiency in patients with EB is typically diagnosed based on lab values



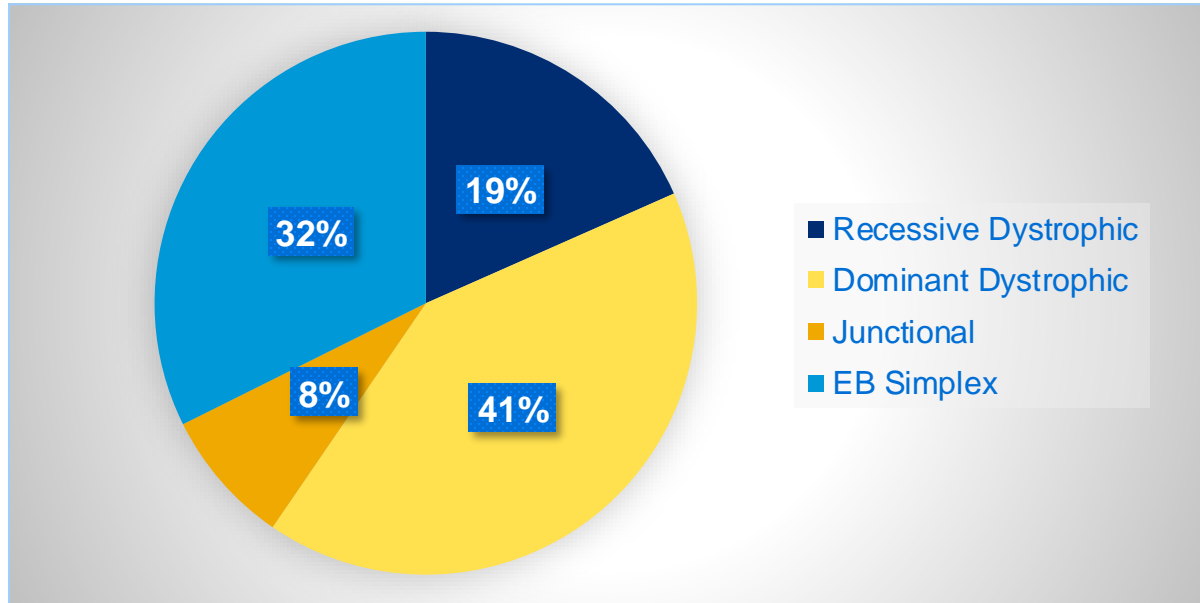
Vitamin C and EB

- An EB clinic in London had a patient diagnosed with Vitamin C deficiency
- Found that 32% of patients in their clinic with recessive dystrophic EB had low plasma vitamin C levels
- These patients were mostly adults

Greenblatt DT, Hubbard L, Bloor C, Card D, McGrath JA, Mellerio JE. Vitamin C concentrations in patients with epidermolysis bullosa. *Br J Dermatol.* 2022 Nov;187(5):808-810. doi: 10.1111/bjd.21719. Epub 2022 Jul 22. PMID: 35763388.



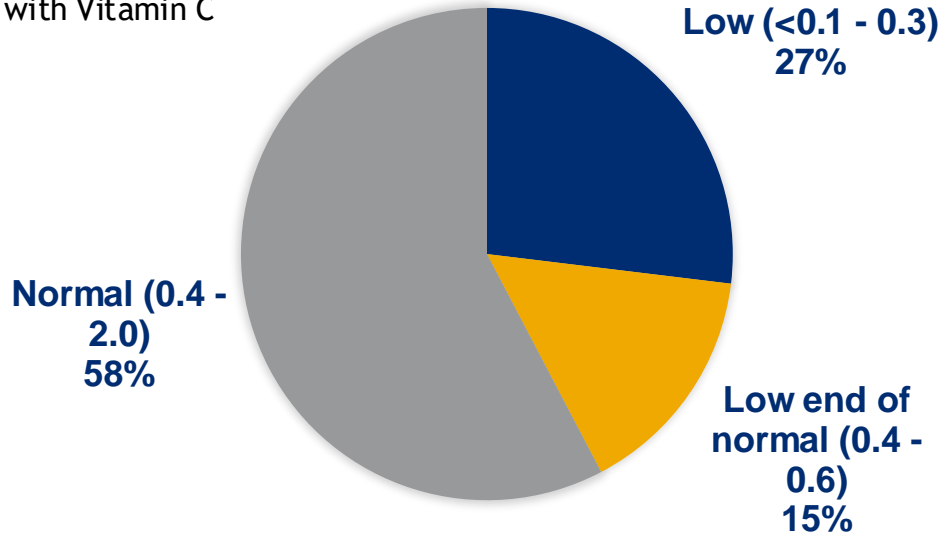
Children's Hospital Colorado EB Clinic



Vitamin C Results

- The EB Clinic at Children's Hospital Colorado began checking vitamin C as part of routine labs starting in 2022

Patients with Recessive
Dystrophic with Vitamin C
results: 26



Vitamin C Results

- To prevent deficiency, the EB Clinic of Children's Hospital Colorado is recommending to start supplementation for all patients with recessive dystrophic at age 4 and up
- Dose: 250 mg daily



Vitamin C Questions

- Looking into changes to lab results before and after supplementation
- Is this dose is adequate to prevent deficiency
- Collecting information on potential side effects
- Collecting other factors that could effect results, including the use of Vyjuvek
- This is ongoing through the rest of 2024



Final Thoughts

- Nutrition has a significant impact on quality of life with an imperative role in wound healing and preventing infections
- High calorie foods, oral supplements and/or tube feedings and vitamin and mineral supplements can help achieve this
- More to learn in the future about Vitamin C

Questions?

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