

# NUTRITION IN EB

Individuals with EB require large caloric intake in help support their wound healing. Consultation to a dietician is often needed to help with this goal.

## Reasons for poor Nutrition in EB

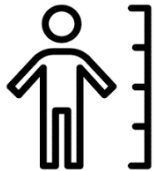


Individuals with severe EB, especially those with recessive dystrophic EB or junctional EB, are at risk of malnutrition and require nutritional support. There are several reasons for poor nutrition in a child with EB:

- Eating challenges, including:
  - Mouth sores
  - Reduced ability to self-feed
  - Poor appetite (does not feel hunger)
- Fragile mucosal lining of the gastrointestinal tract “gut”, which causes:
  - Ulcers, blistering, and pain
  - Difficulty swallowing
  - Esophageal strictures
  - Reduced absorption of nutrients
- Increased metabolic rate and energy requirements due to:
  - Excessive loss of heat and nutrients through the fragile skin
  - High skin turnover and wound healing
  - Frequent infection
  - Inflammation (red, sore and swollen tissue)
- It is important to provide nutritional support, as malnutrition is associated with:
  - Poor growth
  - Delayed puberty
  - Poor bone health
  - Fatigue
  - Limited ability to be physically active
  - Potential for poor quality of life



It is important for children with EB to be evaluated regularly by a dietician in order to assess their nutritional requirements and provide an individualized nutrition plan.

## Growth



- In cases where growth is not ideal (this means the weight or height curves are flat or a child has dropped on a curve) then supplementing with formula either by mouth or using a tube may be advised.
- Tubes can go through the nose, a nasogastric (NG) tube, and are short term plans.
- Tubes can go through the stomach, a gastrostomy (G) tube, and are for long term nutrition support, for example sometimes in children with severe dystrophic EB.

# NUTRITION IN EB

<b>Nutritional Deficiencies</b> 	Regular monitoring of nutrient levels, including iron, calcium, vitamin D, phosphate, vitamin A, vitamin E, zinc, selenium, B vitamins like folate and vitamin B12, urea and carnitine.
<b>Constipation</b> 	<ul style="list-style-type: none"><li>• It is common for children with EB to have problems passing stool</li><li>• Fluids are important to help pass stool – especially if taking medications to soften stool.</li></ul>
Useful Websites/links: <ul style="list-style-type: none"><li>• <a href="http://www.swrwoundcareprogram.ca">www.swrwoundcareprogram.ca</a></li><li>• EB Resources, including EB handbook: <a href="https://www.debracanada.org">https://www.debracanada.org</a></li></ul>	

*Disclaimer: Unless stated otherwise, information contained in this document is taken from Epidermolysis Bullosa: A Handbook for EB Patients and Families, Developed by the Section of Dermatology at the Hospital for Sick Children with the Support of DEBRA Canada and Sick Kids Hospital Department of Dermatology EB Expert Team - all content used with permission. This document was created by SWRWCP (August, 2019).*

