

Appendix 4: Exclusive Enteral Nutrition Protocol

Exclusive Enteral Nutrition (EEN):

EEN involves the use of a nutritionally complete liquid diet given exclusively (instead of usual food and fluids) for a defined period of time to induce remission of active Crohn's disease (CD). In contrast, the term supplementary enteral nutrition refers to the provision of a certain volume of an enteral formula in addition to standard diet.

Indications for EEN:

- ◆ Initial therapy for all children and adolescents with new diagnosis of CD, regardless of the predominant location of disease.
- ◆ Secondary therapy in children with long-standing CD who have not maintained control with standard drug therapy/therapies. In this case EEN is added to the patient's regimen in addition to the patient's other therapies.
- ◆ **NB:** EEN appears to be less efficacious in ulcerative colitis (UC) but is not contraindicated in this condition.

Initiating EEN:

- ◆ Prior to and/or after diagnosis, discuss EEN as a therapeutic option to induce remission with the patient/family. This discussion should include review of the pros and cons of EEN, and comparison of this therapy with the alternative drug regimens.
- ◆ Provide the handout **Guide to nutritional therapy for patients with Inflammatory Bowel Disease**
- ◆ Collect growth data, including accurate height and weight measurements. Review past growth patterns and plot all available parameters on an appropriate growth chart.
- ◆ Based upon the child's current age, weight and growth pattern, the child's specific fluid and caloric requirements will need to be calculated to determine the volume and type of formula required per day.
- ◆ The formula volumes given each day should be progressively increased over the first 3-4 days. This helps to prevent initial symptoms of feed intolerance, such as nausea, bloating or fullness. A standard approach involves the administration of 50% of the required volume on day one, 75% on day 2 and then full volume by day three. A plan for the ongoing administration of formula is worked out in a way that suits the child and family.
- ◆ Children with severe nutritional impairment at the time of commencing EEN may be at increased risk of developing refeeding syndrome. Slower introduction of EEN, along with appropriate monitoring, would be indicated in this setting.

Other issues during EEN:

- ◆ Emphasise that no additional food is permitted during the period of EEN. Additional water to drink is encouraged.
- ◆ Numerous practical issues can arise during the period of exclusive nutritional therapy, such as managing EEN at school. Offer practical strategies to support the child/family at home and school. Almost every conceivable issue has been encountered in the past – there are many tips and techniques to cope with and manage these.
- ◆ Some of the common issues are dealt with in the **Guide to nutritional therapy for patients with IBD**. In addition, common issues should be mentioned and discussed prior to starting EEN. Dealing with these issues as they arise is undertaken either during support calls or at times of review.
- ◆ There are essentially no side effects related to EEN. However, some children may have some initial bloating or early satiety during the first few days. Avoiding supplements or adjunct agents, such as iron, during the initial stages can be helpful. A brief period of acid suppression can help with resolution of these symptoms and assist the initial tolerance of the formula. Often times, children have slightly semi-formed motions whilst on EEN.
- ◆ Children may report a white coating on the surface of their tongue. Although thrush may need to be excluded, this generally resolves with good oral hygiene. Children should maintain regular dental hygiene during EEN, with brushing of teeth and tongue 2-3 times daily and use of an age-appropriate mouth wash. In addition to providing a chewing action, the prudent use of sugar-free gum helps to stimulate saliva production.

EEN Formula:

- ◆ Polymeric (intact protein) formulae are preferred over elemental formulae, as they have better taste acceptance. Similar efficacy is seen with either formulae.
- ◆ Most children are able to take a polymeric formula orally: occasionally a nasogastric tube is required for part or all of duration of the EEN period.
- ◆ Various formulae can be used. Children should have the opportunity to taste the various options to assess which they prefer.
- ◆ After establishing the appropriate formula for each child, a special authority number will need to be obtained. The formula requirements can then be provided on a script. Parents will be able to obtain supplies from their local community pharmacy or home delivery service. Provision of a small initial supply of formula is encouraged.

Ongoing review and follow-up during period of EEN:

- ◆ EEN is usually recommended for an eight week period. Shorter periods may be indicated in certain circumstances, such as in the management of a disease exacerbation subsequent to diagnosis.
- ◆ Close multi-disciplinary team support during EEN is essential to ensure that compliance is maintained throughout the length of the nutritional therapy, and to optimise the success of the therapy. Close day to day support should be provided by phone or email contact with members of the team, on an as necessary basis.
- ◆ Regular multi-disciplinary review should be undertaken during the period of EEN. A standard frequency involves review every two weeks: however in some circumstances review will be required more frequently. At review visits compliance with feeds will be assessed, any difficulties with the regimen managed, growth reviewed, general progress assessed and volumes adjusted accordingly. Inflammatory markers may be measured at regular intervals during the period of EEN to monitor the response to therapy.
- ◆ In addition to support provided by the treating team, peer support may be appropriate and can be arranged on an individual basis. Usually this involves identifying a child of a similar age, and/or from a similar area geographically, who is then able to make contact (email/phone/direct) with the child who is just starting on EEN. Although not all children are comfortable with this initially, it should be always offered or mentioned.

Completion of EEN and recommencement of normal diet

- ◆ Prior to the completion of the prescribed period of EEN, it is important to start discussing and planning the reintroduction of normal diet. The best accepted manner in which to do this is the reintroduction of one small meal per day for 3 days, followed by a second meal and so on. During this period the volume of enteral formula is slowly reduced. [See Appendix 5: **Reintroducing food after exclusive enteral nutrition therapy**].
- ◆ There is no evidence to support the gradual introduction of one food at a time, or for the introduction of fluids before solids following a period of EEN. The former method often becomes very confusing for parents and the child because it introduces a fear associated with particular foods in their ongoing diet. It is very uncommon for a child with CD to have difficulties associated with the reintroduction of particular types of foods.
- ◆ Following the re-introduction of normal foods, ongoing supplementary enteral nutrition is encouraged. Maintenance of a small ongoing volume (e.g. 500-750 mls daily) may be sufficient to maintain remission.
- ◆ Many children will commence maintenance medical drug therapy prior to or at the completion of EEN.