

Exclusive Enteral Nutrition for children with Crohn's Disease

Information for patients, parents
and carers



leeds children's
hospital

caring about children

Introduction

This leaflet has been written to answer some of the questions you might have about Exclusive Enteral Nutrition (EEN) as a treatment of crohn's disease.

What is crohn's disease?

Crohn's disease is a condition which causes inflammation in any part of the gastrointestinal tract. It can result in symptoms such as tiredness, tummy pain, diarrhoea (with or without blood) and poor growth.

What is Exclusive Enteral Nutrition?

Exclusive Enteral Nutrition is a treatment option for children with Crohn's Disease. It involves replacing all food with nutritionally complete drinks. These drinks will provide all the energy, protein, vitamins and minerals your body needs and are available in a range of different flavours.

If you are not feeling well it can be difficult to take all the drinks so you may need to have your special diet through a tube. This is called a nasogastric tube and it is passed through your nose down into your stomach. The liquid is then given using a pump which can be carried around with you in a special rucksack.

Why do we use EEN?

EEN is used to treat active Crohn's Disease. It aims to get your disease into remission or to reduce the inflammation in your gut.

After completion of EEN, continuing on a maintenance dose of supplements can also help to keep your body in remission.

EEN is safe and for some people may be a good alternative to a medication such as steroids.

How does it work?

The exact reason why EEN reduces inflammation in the gut is still unclear and is still being researched.

It may work by changing the mix of bacteria that live in the gut by directly reducing inflammation, by removing specific components of food and/or giving the gut a chance to heal while providing balanced nutrition.

Are there any side effects?

You may feel hungry when you first start the diet and if this remains the case when you are managing your target volume, please contact your dietitian to discuss.

You may be left with a strange taste in your mouth, make sure you brush your teeth regularly and keep drinking extra water.

If you take your drinks too quickly it could make you feel sick. Try and drink more slowly, over about 20 minutes.

Can I have anything else to eat or drink?

Yes....

- Tap water or bottled water (avoid flavoured water)
- Full sugar 7UP or Sprite (avoid "diet" varieties)
- Full sugar diluting squash
- Fox's Glacier Mints / full sugar Polo mints / clear boiled sweets

It is important that you have enough fluids as well as the special drinks, as being dehydrated can make you feel tired and give you a headache.

How long do I need to follow it for?

You will need to take the liquid diet for at least six weeks (and sometimes up to eight weeks) from the day you reach your full target volume. After this your dietitian will discuss re-introducing solid food gradually. It is also recommended that even when you are back to eating normally, you should continue with a small number of the drinks in addition to your usual diet.

How will we know if the diet is working?

- Any symptoms you had before the diet will start to improve e.g. loose stools, tummy ache
- You will start to have more energy and feel stronger
- You will have more of an appetite
- You will gain weight

If there is no noticeable benefit after two weeks on full target volume we may need to consider other treatment options.

Your EEN Plan is:

Supplement drink/s:

Number of bottles/cartons per day:

Start date:

End date:

Hints and tips:

- The drinks are best taken when cold, straight from the fridge
- Alternatively, milk based supplements can be gently heated for a warm drink (do not boil as it will affect the vitamins and minerals)
- Supplements can be frozen in ice cube trays or ice lolly moulds and then eaten like ice cream or sorbet
- Crushed ice can be added for a change in texture or use a blender
- You can mix the juice based drinks with full sugar 7UP or Sprite
- Have the drinks slowly over about 20 minutes
- Clean your mouth more often to keep your mouth feeling fresh
- You shouldn't need an additional vitamin supplement whilst on the liquid diet however if you do, your dietitian will advise you on a suitable preparation
- Make a chart so you can cross off your progress. Consider giving yourself a treat when you reach small targets e.g. a packet of stickers, nail varnish, magazine etc.

Some useful websites include:

www.nacc.org.uk

(National Association of Crohn's and Colitis)

www.cicra.org

(Children with Crohn's and Colitis)

Contact us:

Please do not hesitate to contact us if you have any questions or are finding things difficult.

Your dietitians are:

Catherine Oswin

(Mon-Wed): 0113 392 0628

Charlotte Hewitson

(Wed-Fri): 0113 392 0631

Reintroduction of foods following EEN

After six weeks your dietitian will advise you on re-introducing foods back into your diet. Once you are back on normal diet it can be beneficial to continue a maintenance dose of the nutritional drinks and your dietitian can advise you on this.

The aim is to re-introduce solid foods gradually over two weeks whilst reducing the amount of liquid feed you are drinking.

Food types and amounts:

- Initially only have foods which are low in fibre:
 - remove skins and pips from fruit and vegetables
 - choose white bread, pasta and rice instead of wholegrain
 - avoid nuts, beans and pulses
 - avoid high fibre breakfast cereal e.g. All Bran, Weetabix, porridge, Shredded Wheat
- Avoid foods that contain a lot of fat and spices e.g. fried foods, curries and takeaways
- Take time to eat your meals slowly and chew well
- Eat small, regular meals and snacks rather than be tempted to overeat

Suggested feed volume:

Days 1-4

Aim for $\frac{3}{4}$ of your usual volume of drinks/feed bottles per day

Days 5-8

Aim for $\frac{1}{2}$ of your usual volume of drinks/feed bottles per day

Days 9-12

Aim for $\frac{1}{4}$ of your usual volume of drinks/feed bottles per day

Day 13 onwards

Normal diet + maintenance dose of 1-2 bottles per day

Suggested meal ideas at the start of food reintroduction

Breakfast:

Rice Krispies with milk or white toast with margarine/butter

Mid-morning:

Drink/snack

Lunch:

White bread sandwich with ham, tuna, cheese

Plain biscuit

Apple without the skin

Yoghurt

Mid-afternoon:

Drink/snack

Evening:

Chicken, pork, beef, lamb, fish

Mashed potato, jacket potato without the skin, white rice or pasta

Small portion of vegetables without skin or seeds

Jelly/yoghurt



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