Nutrition
in
Epidermolysis Bullosa

For children over 1 year of age

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About this booklet

This booklet explains the nutritional problems which can occur in Epidermolysis Bullosa (EB) and offers practical advice to minimise their negative impact. For those with no specific problems, it gives advice about normal, healthy eating.

Unfortunately, a short booklet like this can give only general advice and cannot provide answers to every situation. In order to aim for the best possible nutrition for your child, the advice of a paediatric (children’s) dietitian should be sought. An individualised plan can then be drawn up and reviewed regularly to ensure that it continues to be realistic and feasible.

If you would like further help, please contact Lesley Haynes, who can offer advice. If you wish, she can put you into contact with a dietitian local to your home.

Please note: EB affects boys and girls equally, but for ease of reading, the child is referred to as “he” throughout.
Introduction

Nutrition matters! Good nutrition is one of the most important, yet frequently underestimated, aspects of EB management throughout life. This is especially so in children with the more severe forms of EB, as they can rarely consume enough food to satisfy the twin needs of growth and prompt skin healing.

Achieving good nutrition in EB is problematic largely due to:

- difficulties in chewing and swallowing
- an increased need for nutrients to compensate for those used in healing
- extremely painful bowel movements with, and without, constipation
- anaemia (lack of iron)

Although there is no “special” diet which can cure EB, recent research has proved that improvements in nutrition can result in much better growth, greatly reduced levels of stress and frustration surrounding eating and a significantly improved quality of life for both EB sufferer and family alike. Increased resistance to infection and better wound healing should also result from improvements in nutrition.

Most regrettably, the above information does not apply to the Herlitz type of junctional EB. In this type of EB, the complications of the disease prevent any long-term benefits of nutritional modifications.

Good nutrition begins at birth and information on feeding babies with EB can be found in:

Nutrition for Babies with Dystrophic Epidermolysis Bullosa
by Lesley Haynes SRD
Published by DEBRA
Why nutrition is so important

How well (or badly) we are nourished is one of the most important factors which influence the health of us all. Thanks to the adaptability of the human body, it can survive significant deprivation and yet continue to function. However, short- and long-term health, as well as feelings of general well-being are undoubtedly jeopardised when nutrition is poor. It makes sense for all of us to try to eat as well as possible, both for current good health and as an “insurance policy” for the future. It is all matter of balance, so that we consume a good variety of nutrients every day.

A nutritious diet provides all the nutrients that are necessary to keep the body fit and healthy, and to enable the child to grow normally. Food is composed of many nutrients, and these are usually categorised as :-

- Proteins
- Fats
- Carbohydrates
- Vitamins
- Minerals
- Fibre
- Water

Put very simply, most nutrients are channelled into growth and repair (normal “wear and tear”), and to supply energy (calories). In practice, many foods comprise more than one nutrient. For example, full cream milk contains protein, fat, carbohydrate and calcium; bread contains carbohydrate, protein and fibre; cheese contains protein and fat. On the other hand, some foods contain predominantly one nutrient. For example, sugar is virtually pure carbohydrate; butter is almost entirely composed of fat.

Enjoying good nutrition means getting the balance right, by including all of the above nutrients every day. This is not as difficult as it sounds and there are numerous permutations of food which can be eaten to provide a balanced and nutritious diet.

The nutrients needed for good nutrition are :-

Proteins are essential constituents of all living cells. They are necessary for growth and continual repair, and are particularly important during infancy and childhood to build strong, healthy body tissues. Wound healing requires a good protein intake.

The main sources of animal protein are meat, fish, eggs and dairy products (milk, cheese, fromage frais and yogurt). Foods such as pulses (peas, beans, and lentils), nuts and cereals contain vegetable protein. A vegetarian diet needs to be planned carefully to ensure its adequacy for any child, especially an EB child. Nuts (except for smooth nut butters)
should not be given to children under the age of 5 years in case they inhale them or choke.

**Fats** are the most concentrated source of energy in the diet. They also form part of the essential structure of all living cells. Fats are only “bad” foods if they are taken in amounts which are surplus to the body’s energy needs, leading to excess weight gain. Some EB sufferers are relatively immobile and may depend on a wheelchair for their mobility. Lack of exercise may lead them to become overweight, in which case they should reduce their fat intake. For most severely-affected EB children, however, fats and fatty foods are useful sources of energy which allow the protein in their diet to be used efficiently.

Butter, margarine, cream, oil, lard and suet are obvious sources of fat. Less obvious sources are full cream milk, full fat yogurt, cheese, fromage frais, ice cream, meat (especially where there is visible fat), eggs, oily fish (sardines, pilchards, mackerel, salmon), avocado pears, nut butters and chocolate.

**Carbohydrates** form part of the structure of all living cells. They comprise a large group of energy-providing foods some of which (cereals, breakfast cereals, flours, pasta, bread, potatoes, fruits and pulses) also provide fibre, vitamins and minerals. Other members of this group are useful just as a source of energy (biscuits, sugar, sweets, glucose, jam, honey and syrup). Puddings and cakes are valuable principally for their energy content, but can be useful protein sources if they are made with eggs and milk products.

All carbohydrates are important in the EB diet. The sweet ones (biscuits, sugar etc.) should be included with, but not instead of, the less sweet ones (cereals, potato etc.). See also section on Tooth Decay. If overweight is a problem, the sweet carbohydrates should be limited.

**Vitamins** are essential for health and for the normal functioning of the body; for healthy people, they are usually required in only very small quantities. Without vitamins, many of the body’s most basic processes, such as extracting energy from food or building new body tissues, cannot take place.

There are many vitamins, each with a highly specific function, for example:-

**Vitamin C** (ascorbic acid) is important in rapid wound healing. Concentrations of Vitamin C in foods vary widely – for example, oranges, kiwi fruit and blackcurrants are well-known as rich sources of Vitamin C. It is also present in potatoes and green vegetables and helps the body to absorb and use iron.
**Vitamin A** is found mainly in liver, carrots, milk, margarine and butter. Dark green, red and yellow vegetables contain a substance called retinol which can be converted to vitamin A in the body. Vitamin A is required for the maintenance of healthy skin and eyes.

**The B group of vitamins** is found in dairy foods, meat, eggs, bread and cereal products and potatoes. Different B vitamins have different functions e.g. promoting the efficient use of energy from carbohydrates, maintaining healthy blood and skin and promoting the efficient use of protein.

**Vitamin D** is essential to build strong bones and teeth. It is found in margarine, oily fish, evaporated milk, eggs and liver; the richest source is fish liver oil. The action of sunlight on the skin produces Vitamin D in the body. Because EB children often get less sunlight exposure than their unaffected peers, it is important to ensure that they take enough Vitamin D and a supplement is usually advisable.

Multi-vitamin supplements are often recommended for those with EB, because they have difficulty eating normal amounts of foods, and because their requirements for some vitamins are believed to be higher than those of non-sufferers. However, it is important to appreciate that excessive intakes of some vitamins can be harmful; you should always ask for dietetic advice regarding the most appropriate supplements for your child.

**Minerals**, like vitamins, are essential for many body processes, and the functions of about twenty minerals have been discovered. Each has a specific role, for example iron is an essential component of blood, zinc is important in wound healing and in helping the immune system to operate and selenium is vital in protecting cell membranes against damage. In EB, there is often a need for extra minerals to fuel the healing process and compensate for those lost in open or infected wounds.

**Fibre** (or roughage) is the part of food which passes through the body without being absorbed. Far from being a useless waste product, it helps to maintain the correct levels of fats in our blood as well as promoting the right balance of bacteria in our gut and helps to prevent constipation.

**Water** - Everyone knows what this is, but few of us drink enough of it! To keep the kidneys and bladder healthy and to help dietary fibre to work properly, we should drink plenty of fluid every day, especially in hot weather. A desirable intake depends on age, and can mean drinking 5 – 10 cups per day. This can be as plain water, or as other fluids for example milk or juice (ideally fresh and diluted with water to minimise tooth decay - see page 10).
A suggested meal plan for a growing child

**Breakfast**
Cereal (preferably one containing fibre, eg. Weetabix, or porridge) plus milk*
Bread or toast (preferably wholemeal) with butter/margarine, honey, jam, marmalade, peanut butter
Milk*

**Mid-morning**
Milk* or fruit squash plus fresh fruit, biscuit or cake

**Lunch**
Meat with gravy or fish and sauce
Potato, rice or pasta
Two vegetables
Or a dish such as lasagna, shepherd’s pie, macaroni cheese
Fresh or tinned fruit, ice cream, custard
Milk*, water, fresh fruit juice or fruit squash

**Evening**
Egg, ham, cheese, baked beans, sardines, liver sausage
Jacket potato or wholemeal bread and butter/margarine
Yoghurt or fromage frais or milk pudding, e.g. custard, rice
Milk*, water, fresh fruit juice or fruit squash

**Bedtime**
Milk* or cereal and milk*

* Aim for 500ml full fat milk per day unless excessive weight gain is a problem, then use semi-skimmed milk. Skimmed milk is unsuitable for small children unless on the advice of a dietitian.
Causes and consequences of nutritional problems in severe EB

For children with the more severe forms of EB, good nutrition is especially important because :-

- nutrients, for example protein and iron, are lost through open, weeping wounds
- poor iron status causes anaemia, which in turn leads to apathy, reduced appetite and poor wound healing
- extra nutrients are needed for rapid healing and to fight infection
- last, but by no means least, hunger and malnutrition cause much unnecessary misery to both the child and his carers

Unfortunately, the problems associated with their EB prevent these children consuming even normal amounts of food, when what they urgently need are above-normal amounts of many nutrients. It is not surprising that, without prompt nutritional intervention, they have problems consuming enough food to grow, to combat infections and to heal quickly.

The following diagram illustrates the interactions between the causes and consequences of nutritional problems in severe EB.

The impact of nutritional problems in severe EB

Gums and teeth

Problems with gums and teeth are hard to avoid when the mouth is fragile and good oral hygiene is difficult to maintain. However, fillings and extractions are difficult to carry out in EB and involve additional pain for the child, so as much as possible, try to keep the teeth and gums in a healthy state. Be advised by your dental specialist regarding fluoride supplements and suitable mouthwashes and toothbrushes. Spacing meals and snacks and limiting sweet foods to mealtimes, helps to keep acidity levels in the mouth low so limiting erosion of tooth enamel. For further information, see DebRA booklet, A Guide to Dental Care.

Mouth and oesophagus

Blistering in the mouth and oesophagus, painful swallowing, tightness of the mouth and an immobile tongue, tooth decay and sore gums all mean that eating is often painful, tiring and tedious. Slow and laborious eating means
that one mealtime frequently drifts seamlessly into the next. Parents and carers experience enormous stresses in trying to feed their child adequately. Adjustments can be made both to the texture of food to make it easier to swallow, and to its nutritional composition, so that as much nutrition as possible is packed into as small a volume as possible (see pages 12 and 17).

It is advisable to set time limits on meals to avoid reinforcing the negative aspects of food and eating, and to minimise the frustration felt by child and carers alike. A realistic balance should be struck between encouraging and helping him to finish his meals and snacks, and allowing time for play and other social activities. Give praise for small achievements and never scold or force-feed. Spacing mealtimes and avoiding continuous “grazing” will also help the child to develop an appetite, is less likely to promote tooth decay (see below) and stimulates his gut muscles to work properly, so reducing the likelihood of constipation (see below and page 14).

Bowels

Regardless of the severity of their skin problems, many EB children experience extremely painful bowel movements and are reluctant to open their bowels. This is one of the most under-treated and distressing aspects of EB. At best, constipation makes EB children feel listless and apathetic, and in worse situations, it has a devastating effect on appetite and quality of life. The vicious cycle illustrated in the diagram on page 9 can be established very early and it is important to recognise this, introducing age-appropriate laxatives and fibre sources (see pages 14 - 16).

Anaemia

Children with EB become anaemic for two main reasons. Firstly, they continually lose blood from wounds on the surface of the body, as well as from internal wounds in the mouth, oesophagus and anus. Secondly, meat is the best dietary source of iron, but EB children often find meat impossible to chew and swallow. An iron supplement should be prescribed as soon as deficiency is confirmed (by a blood test).

Coping with the problems

Chewing and swallowing difficulties
A sore mouth and narrow throat mean that some EB children can manage only very soft or pureed foods. Such a diet is boring if it relies on soup and ice cream, but by including suitable family dishes, it can be made more varied and appetising. Some children find cool, cold or lightly frozen foods soothing and easier to manage than hot foods.

Pureed meals look much more attractive if each food is pureed separately, and if colourful ones such as carrots, baked beans and peas are used to contrast with the colour of the meat component. Children often like to see food before it is pureed so that they know that they are having the same as everyone else.

Some dishes can be made in bulk and frozen in individual portions for use when the family meal is not suitable for pureeing. It is best to use soup, milk or sauces as the liquid to puree foods. If water is used, it dilutes the nutrient content of the dish making it taste bland. If possible, do not sieve food as this reduces its fibre content.

Take advantage of the high protein content of eggs, meat, fish and cheese and dishes containing these, and add calories in the form of butter, margarine, oil, mayonnaise, cream and evaporated milk. For example:

- Add a knob of margarine or a tablespoon of single cream to scrambled eggs, fill an omelette with cream cheese or grated cheese mixed with mayonnaise.
- Try poached fish (be sure to check that all bones have been removed) in white or cheese sauce to which cream has been added.
- Add cream to custard, yogurt and fromage frais.
- Add an egg and evaporated milk or cream to home-made milk pudding before baking.
- Make full cream milk more nutritious by adding 4 tablespoons skimmed milk powder per 500ml.
- Replace some of the water in a jelly recipe with a small tin of evaporated milk.
- Try home-made milk shakes (see Appendix 1)

Make the most of the energy content of sweet foods such as sugar, jam, honey, chocolate spread and syrup; as well as spreading these on to bread and biscuits, they can be added to custard, yogurt and fromage frais.

The sample menu on page 17 shows how to incorporate some of these ideas into mealtimes.
Nutritional supplements (see Appendix 2)

If chewing and swallowing are particularly difficult for your child, the ideas above may only partly satisfy his increased nutritional requirements. It is also unrealistic to expect busy parents and carers to enhance meals sufficiently often to make a significant impact on the severely affected EB child’s intake. So, full use should be made of the wide variety of available commercial nutritional supplements. Many of these can be obtained on prescription from your general practitioner (GP). A number of these are in the form of sip feeds containing a balanced variety of nutrients, which are attractively packaged, often in a tetra-pack with a straw. Their resemblance to supermarket brands makes them more acceptable to EB children who are then willing to take them to school to supplement or replace a meal or break-time snack.

Specially-manufactured energy supplements of pure carbohydrate, fat, protein, or a combinations of these, can also be obtained on prescription from your GP. These taste very bland and can be added to both sweet and savoury foods.

Children tire very quickly of taking supplements, so it is important to “ring the changes” frequently. Keep in regular contact with your dietitian so that she can tell you when new products are launched and offer samples to take home and taste. To ensure that your child derives the greatest benefit from supplements, always ask your dietitian for advice on the most appropriate ones and the best ways in which to use them.

Appendix 2 lists the range of commercially-available supplements, most of which are available on FP10 prescription.

Constipation

Some children have hard motions (also known as stools and faeces) and they are technically constipated according to the medical definition. However, other children feel pain and avoid opening their bowels even when their motions are fairly soft. For the purposes of this booklet, both situations will be called “constipation”, as the management is similar for each.

The negative effect that chronic constipation exerts on eating and on quality of life in general is greatly underestimated. The anal skin is so delicate that even a “normal” motion has the potential to tear it, so pain is often felt every
time the child opens his bowels; he may also pass blood. He learns very quickly to oppose or ignore the urge to open his bowels (often for several days). He may be unable to completely resist passing a small motion, but retain the remainder which becomes progressively drier and harder. A bowel which is loaded with hard "rock-like" motions makes the child feel full, bloated and very uncomfortable. This situation reduces his appetite and so he eats less, to the extent that he becomes malnourished and his growth is impaired. Less food means less residue in the bowel to stimulate movement and so on as the vicious cycle develops (see page 9).

The child may feel abdominal pain as soon as he is asked to sit at the table for a meal. He may refuse to do this or refuse to eat anything, and this is often mistaken for naughtiness and manipulative behaviour. In fact, the smell of food and the anticipation of eating are often enough to cause griping abdominal pains, as the muscles in the bowel try to move the motions along to make room for the next meal.

The two conventional ways of managing constipation are :-

- by taking more fibre (and fluid) in the diet and / or
- by taking laxatives (under medical supervision)

Both these approaches influence the consistency and bulk of the motions and affect the speed at which they pass through the gut. Increases in dietary fibre and fluid can often very successfully help constipation and for those whose EB is relatively mild, and who can eat the appropriate foods while still maintaining satisfactory growth, this should be the treatment of choice. The following guidelines give general information about including more fibre in the diet. More detailed information can be found in "Increasing Fibre Intake for Children with EB" available from Lesley Haynes.

**Guidelines for increasing the fibre content of the diet**

- Include more cereal fibre by using wholegrain breakfast cereals such as Weetabix, Shreddies, Bran Flakes, Ready Brek, porridge. Try wholemeal and pumpernickel (German rye) bread, wholegrain biscuits e.g. Digestive, flapjacks and cereal bars, brown rice and wholemeal pasta. Try using 50% wholemeal and 50% white flour in home baking.
- Eat more fruit, especially raw. Leave the skin on apples, pears, apricots, peaches, grapes etc. Include prunes, figs, dried apricots, raisins, sultanas.
- Eat more vegetables, especially raw where possible. Pulses (peas,
beans, lentils) tinned mushy peas, pease pudding, baked beans and sweet corn. The skin of jacket potatoes is delicious!
- Don’t forget to drink plenty of fluids every day, preferably water.

A word of caution about high fibre diets

It is important to appreciate that it is unrealistic and inappropriate to advise a high fibre diet when the child has severe EB because:
- Foods such as muesli, wholemeal bread, fresh fruit and salads are difficult or impossible to swallow.
- High fibre foods are comparatively low in energy. Severely affected EB children need a high energy intake to grow properly and heal.
- The bulky nature of such a diet makes it very filling and may reduce the appetite for more valuable foods.

Other sources of fibre

Children who are unable (or unwilling) to eat conventional forms of fibre (as outlined above) may benefit from:
- A pure fibre source such as Resource Benefiber (Novartis). This is tasteless and so very “child-friendly”, mixing well with any liquid.
- A fibre-enriched supplement such as one of those listed in Appendix 2.

These can be obtained on prescription from your GP. The dietitian can advise on the best choice of feed or dose of pure fibre, depending on your child’s age and specific requirements.

Laxatives and softeners

These should be used with care when a child is constipated. Giving, or increasing a softening laxative (e.g. lactulose) may only make the situation worse as the loose motions are passed leaving the “rocks” behind. Loose motions can also mean “accidents” when the child sneezes or laughs and motions are accidentally leaked. If the bowel is full of “rocks”, a stimulant laxative (e.g. senna [Senokot]) may increase the abdominal pains as the muscles lining the bowel are made to squeeze on the hard motions. It is very important to ask the advice of your child’s EB specialist regarding laxative dosages.
# Ideas for maximising the nutritional content of the EB child's diet

## Breakfast

| Cereal         | Choose high fibre cereal and sprinkle with sugar  
|                | Stewed prunes                                     
| Bread or toast | Choose wholemeal bread and spread generously     
|                | with butter/margarine, honey, jam, marmalade, peanut butter, chocolate spread |
| Milk           | Use full cream milk, fortified milk (see page 12) or a prescribable feed (see Appendix 2) |

## Mid-morning, Mid-afternoon & Bedtime

| Milk           | Use full cream milk, fortified milk or a prescribable feed, soft fruit, biscuit or cake |

## Lunch

| Shepherd's pie | Add milk, butter or cream to potato. |
| Cauliflower    | Serve with cheese sauce to which cream has been added |
| Milk           | Use full cream milk |
| Drink          | Water, fresh fruit juice or fruit squash |
| Pudding        | Fromage frais or yoghurt with added cream or jelly made with evaporated milk |

## Evening

| Macaroni cheese or Fish in sauce or Jacket potato or Quiche or Pizza Baked beans | Add cream to sauce Add cream to sauce Mash centre with liver pate, cream cheese or tuna and mayonnaise Add a knob of butter / margarine |
| Pudding | Banana mashed with cream and brown sugar / chocolate spread |
| Drink | Water, fresh fruit juice or fruit squash |
Naso-gastric tubes and gastrostomy "buttons"

Although some EB children manage to grow adequately by following the advice outlined earlier in this booklet, the severely affected children cannot maintain this in the long term. This is not the fault of parents and carers who make superhuman efforts to nourish their child; it is entirely due to the complications of EB, and mainly to those which affect the mouth and oesophagus. It makes sense then, to deliver at least some of the child's nutrition directly into the stomach, so by-passing the main "trouble spots".

Feeding by naso-gastric tube (a soft, narrow tube which is passed via the nose, down the oesophagus and into the stomach) or gastrostomy "button" (a small device surgically placed in the stomach wall) allows balanced nutrition to be fed directly into the stomach. Naso-gastric tubes are difficult to secure to fragile skin and older children usually object to the attention that they draw, so their use is limited to the very short term. A gastrostomy button, however, is discreetly concealed under clothing. The operation to place it is reversible, and it can be used as much or as little as necessary, depending on the child's oral intake. It offers the "best of both worlds" because the child can eat and drink as much as he is comfortably able to, with the remainder of his nutrition given through the "button". Equally importantly, it can also be used for giving medicines such as iron supplements and for pain relief.

Not a “last resort”

It is entirely natural for carers to feel apprehensive about an operation such as gastrostomy placement, but it should be seen as a positive step rather than as a last resort. Children who struggle for months or years, failing to get enough nutrition become physically weaker and their growth deteriorates to the extent that it becomes increasingly hard, sometimes impossible, for them ever to catch up again with their peers. They and their carers become more and more demoralised about eating and drinking, and they develop increasingly negative associations with food. The limited nutrition that they can take by mouth becomes less enjoyable and more of a chore. If, and when, tube feeding is finally introduced, they are often so relieved to have this pressure removed that they cease to take anything by mouth. This is a great pity because eating and drinking with friends and family are important social skills, and the ability to participate in them should be preserved if at all possible, even if actual intake is small.

A further very important factor in favour of opting for gastrostomy placement sooner, rather than later, is the issue of acceptance of the button by the child. The younger child is much less aware of body image than the older one, and, with appropriate counselling, has few or no acceptance problems.
For gastrostomy placement to have the best chance of success, it should be undertaken before the age of 3 years, and certainly by 5 years. In general, parents whose children underwent surgery later than this, have said that they wish it had taken place much earlier. Although every EB child has his own specific problems which require a personal plan to be drawn up, you may find it helpful to ask your professional advisers to put you into contact with a family whose child has similar problems to yours and who have been through the experience of gastrostomy placement and feeding.

Because the years of childhood and adolescence should be a time of rapid and sustained growth, gastrostomy feeding needs to be viewed as a medium to long-term prospect, if its benefits are to be fully exploited. This means that it is highly likely to be needed until the child has gone through puberty and achieved his full growth and development potential.

Feeding by gastrostomy

It is not advisable to try to pass pureed food through a naso-gastric or gastrostomy tube because of the danger of blockage. Instead one of the many commercially-manufactured tube feeds, which are available on prescription from your GP, should be used. The dietitian will advise on the best choice of feed, depending on the child’s age and specific requirements.

Gastrostomy feeds are often given during the night, being delivered at a constant rate by a small bedside pump, and leaving the daytime hours for food and drinks by mouth. If the child has a particularly sore mouth or finds swallowing very difficult, he can have feeds during the day to replace, or supplement, meals. These feeds can be given using a pump or by gravity, and many children have such a feed at school. After a "good" day, when enough food and drink has been taken by mouth, the gastrostomy feed may be omitted altogether.

Each child should have his individual situation and requirements assessed by the dietitian and a plan drawn up which is compatible with his daily activities. If life with a gastrostomy is to be successful, the plan must be flexible and compatible with the lifestyle of the whole family. This should be reviewed regularly to ensure that the child's requirements are being fully met.
Appendix 1

Recipes for milk-shakes

*These are best served chilled*

**Ice cream milk shake**

- 200 ml full cream milk
- 2 tablespoons skimmed milk powder
- Milk shake flavouring powder eg. Crusha or Nesquik
- 1 - 2 scoops ice cream

Whisk the first three ingredients together until well combined and the milk powder has dissolved. Float ice cream on top.

**Yoghurt shake**

- 150 ml yoghurt, preferably full fat eg. Greek yoghurt
- 3 teaspoons runny honey
- 1 small, ripe banana

Liquidise all the ingredients together until smooth.

**Peach or apricot shake**

- 100 ml evaporated milk
- 100 g tinned peaches or apricots

Liquidise all the ingredients together until smooth.

**Prune and orange shake**

- 75 ml prune juice
- 75 ml orange juice
- 2 teaspoons brown sugar

Whisk all the ingredients together until the sugar has dissolved.

**Banana shake**

- 150 ml full cream milk
- 1 dessertspoon double cream
- 2 tablespoons skimmed milk powder
- 1 small, ripe banana
- 3 teaspoons brown sugar or maple syrup

Liquidise all the ingredients together until smooth.

Appendix 2
Commercially-available nutritional supplements in the UK

Most of these products are available on prescription - check with your dietitian before requesting them from your GP.

This list is complete at the time of publication, however, new products are launched from time to time and brand names may change.

- **Carbohydrate :-**
  - Caloreen (Nestle)
  - Calshake (Fresenius Kabi)
  - Maxijul (Scientific Hospital Supplies)
  - Polycal (Nutricia)
  - Polycose (Abbott)
  - Vitajoule, Quickcal (Vitaflor)

- **Fat :-**
  - Calogen (Scientific Hospital Supplies)

- **Protein :-**
  - Casilan (Heinz)
  - Forceval-Protein (Unigreg)
  - Maxisorb, Maxipro HBV (Scientific Hospital Supplies)
  - Protifar (Nutricia)
  - Vitapro (Vitaflor)

- **Carbohydrate & fat :-**
  - Duocal (Scientific Hospital Supplies)

- **Carbohydrate & protein :-**
  - Resource Puree Appeal (Novartis)

- **Carbohydrate, fat & protein :-**
  - Cal Shake (Fresenius)
  - Pro-Cal (Vitaflor)
  - Promod (Abbott)
  - Scandishake (Scientific Hospital Supplies)

- **Fibre :-**
  - Resource Benefiber (Novartis)

- **Multi-nutrient, fibre-enriched sip feeds :-**
  - Enrich, Enrich Plus and Paediasure with Fibre (Abbott Laboratories)
Fresubin Energy Fibre, (Fresenius)
Resource Fibre (Novartis)
Nutrini Multi Fibre, Fortini Multi Fibre, Fortisip Multi Fibre
(Nutricia)

- Multi-nutrient sip feeds (no fibre) :-
  Paediasure, Paediasure Plus, Ensure, Ensure Plus, Enlive (Abbott)
  Fresubin Original, Fresubin Energy, Provide, Provide Xtra
  (Fresenius)
  Complan (Heinz)
  Clinutren Iso, Clinutren 1.5, Clinutren Fruit, Build Up (Nestle)
  Resource Shake, Resource Junior, Resource Juice, Resource
  Protein Extra (Novartis)
  Nutrini, Nutrini Extra, Fortini, Fortisip, Fortijuice, Fortifresh,
  Fortimel, Sondalis Junior (Nutricia)

- Desserts (no fibre) :-
  Clinutren Dessert (Nestle)
  Formance (Abbott)
  Forticreme (Nutricia)
  Maxisorb Dessert (Scientific Hospital Supplies)
  Resource Dessert Energy (Novartis)

- Fibre-enriched meals :-
  Clinutren Mix Plus Fibre, Clinutren Cereal (Nestle)
  Vitasavoury (Vitaflo)

Many commercially-available tube feeds are also available for use with
gastrostomies and naso-gastric tubes. The advice of a paediatric dietitian
should always be sought when using tube feeds, therefore they are not
listed here.