

**Nutrition  
for Babies  
with  
Epidermolysis  
Bullosa**

**Lesley Haynes SRD**

Specialist Paediatric Dietitian for EB  
Great Ormond Street Hospital for Children NHS Trust  
London WC1N 1JH, UK

**DEBRA**

**13 Wellington Business Park**

**Duke's Ride**

**Crowthorne**

**Berkshire**

**RG45 6LS**

**UK**

**NUTRITION FOR BABIES WITH  
EPIDERMOLYSIS BULLOSA**

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## About this booklet

Good nutrition is one of the most important, yet frequently underestimated, aspects of EB treatment throughout life. Although there is no "special" diet which can cure EB, on-going research shows 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. This is especially important in the early years of life, because growth and well-being in later years are greatly influenced by good weight gain from birth and by early experiences with food.

This booklet describes the nutrients which make up a normal balanced diet and emphasises those foods which are especially important in EB. This is followed by practical information specific to feeding EB babies up to the age of about 18 months.

EB affects girls and boys in equal proportions, but for ease of reading, the baby is referred to as "he" throughout.

A short booklet such as 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.

For information on nutrition for older children, please refer to :-

Nutrition in Epidermolysis Bullosa - for children over 1 year of age,

by Lesley Haynes SRD  
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## **Why is nutrition so important in EB ?**

Good nutrition is important for all of us, whether we have EB or not, and this is especially so during periods of rapid growth eg. infancy. Babies who do not have EB channel most of their nutrition into growth. Because the skin of EB babies is damaged very easily, they need substantially greater amounts of food not only to permit normal growth, but also :-

- to replace the nutrients lost through open wounds or lesions
- to provide the extra nutrients necessary for rapid healing
- to enable the body to fight or prevent infection in damaged areas of skin
- last, but by no means least, to feel well and enjoy a good quality of life

All babies, including those with EB, have "off days", eg. due to teething or minor illness, when food intake is reduced. EB babies can also develop blisters in the mouth and throat which make feeding uncomfortable and reduce food intake, sometimes very significantly. For all these reasons, it is important to make the most of good days and try to give a nutritious diet as often as possible to compensate for periods of poor eating.

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.

## **What is a nutritious diet ?**

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

Proteins	Vitamins	Fibre
Fats	Minerals	Water
Carbohydrates		

Put very simply, most nutrients are used to satisfy the body's need for growth and repair (normal "wear and tear"), and to supply energy (calories). This series of chemical changes which food undergoes in the body in order to maintain life is known as metabolism.

Nutritional requirements for growth and repair are relatively high during infancy, childhood and adolescence. In EB, when blistering and loss of body fluids require constant repair work, the metabolic rate (the speed at which metabolism takes place) is higher than normal and this necessitates a greater intake of nutrients.

A nutritious diet can be achieved with many different combinations of foods; in fact, the more varied the diet, the more likely it is to contain a good balance of nutrients.

## **How you can provide a nutritious diet for your EB baby**

### **Proteins**

Proteins are particularly important during infancy and childhood to build strong, healthy body tissues. In EB, a high protein intake is needed to help in wound healing throughout life.

The main sources of animal protein are meat, fish, eggs and dairy products eg. milk, cheese and yoghurt. Foods such as pulses (peas, beans and lentils), nuts and cereals contain vegetable protein. A vegetarian diet needs careful planning to ensure its adequacy for any child. Nuts (except for smooth nut butters) should not be given to children under five years in case they inhale them or choke.

### **Fats**

Fats are the most concentrated source of energy in the diet. Some EB babies may not be very physically active, but they often need a high energy intake to allow the body to use protein effectively. If they do not consume enough energy from fats and carbohydrates, valuable protein is used as an inefficient and wasteful energy source. Those with small appetites or feeding difficulties should exploit the high energy content of fats and fatty foods by incorporating them frequently into the diet.

Butter, margarine, cream, oil, lard, suet and dripping are obvious sources of fat. Hidden sources are full cream milk, full fat yoghurt, most types of full fat cheese (including fromage frais), ice cream, meat (especially when there is visible fat), eggs, oily fish (eg. sardines, pilchards and salmon), avocados, nut butters and chocolate.

### **Carbohydrates**

Carbohydrates 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 eg. biscuits, sugar, sweets, glucose, honey, jam and syrup. Puddings and cakes are valuable principally for their energy content, but can also be valuable 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 "Sugar and tooth decay".)

### **Fibre**

Fibre or roughage is the part of food which is largely unabsorbed as it passes through the digestive system. Although it has little food value, it is extremely important in assisting normal bowel function and helps to prevent constipation. Fibre is found in wholegrain breakfast cereals, eg. Weetabix, porridge, bran flakes & muesli, wholemeal bread, wholemeal flour, wholemeal pasta, brown rice, pulses, dried fruit and the flesh, leaves, skins and pips of fruit and vegetables. Those with mouth and throat blisters can find high fibre foods difficult to chew and swallow. Citrus fruits (oranges, tangerines etc) and tomatoes may irritate the mouth if it is blistered or sore. A high fibre diet is bulky and filling and consequently can be low in energy, as less total food is eaten. (See section on "Constipation".)

### **Vitamins**

Vitamins are nutrients which are essential for growth and health. For most people, if a sufficiently varied diet is eaten every day, their intake of vitamins is satisfactory. Several vitamins exist and each has a specific function in the body. For example:-

*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 by the body to vitamin A. Vitamin A is needed to maintain healthy skin and eyes.

*The B group of vitamins* occurs in dairy foods, meat, eggs, bread and cereal products and potatoes. Different members of the group have different functions eg. promoting the efficient use of energy from carbohydrate foods, maintaining healthy blood and skin and aiding protein metabolism.

*Vitamin C* is found mainly in fruit, especially citrus fruit and some vegetables, eg. green vegetables and potatoes. Vitamin C is important in wound healing and helps the body to absorb iron.

*Vitamin D* helps to build strong bones and teeth. It is found in butter, margarine, oily fish, evaporated milk, eggs and liver, but the richest source is fish liver oils. The action of sunlight on the skin produces vitamin D in the body.

Those with EB often have difficulty eating normal amounts of food. Also, their vitamin requirements are likely to be higher than for non-sufferers. For these reasons, vitamin supplements are often prescribed.

*Excessive intakes of some vitamins can be harmful. You should always ask for dietetic advice regarding the most appropriate supplements for your child.*

### **Minerals**

Minerals, like vitamins, are essential for health and growth and a well balanced diet usually provides adequate amounts for normal requirements. Minerals of special importance in the EB diet are iron and zinc.

*Iron* is needed to keep the blood healthy and to prevent anaemia. Supplementary iron is often needed in EB to replace losses from skin lesions. Babymilks contain iron and some manufactured baby foods such as rusks and savoury meals are fortified with iron. The main sources of iron in the diet are meat (especially liver, kidney and corned beef), bread and fortified breakfast cereals.

*Zinc* is vital for rapid wound healing. It also has an essential role in many complex metabolic processes. In EB, the healing process is often continuous and zinc supplements are frequently required. Zinc is found in a variety of foods, particularly protein foods such as meat and dairy products.

*Iron and zinc supplements can be prescribed. Ask for dietetic advice as to the need for, and best type of, supplement for your child.*

*Calcium*, together with vitamin D, builds healthy bones and teeth. It is also needed for normal muscle and nerve functioning and blood clotting. Calcium is found in milk and milk products such as cheese and yoghurt. Breast and formula milks supply plenty of calcium and many EB children receive enough calcium from milk and milk products, so extra supplements are not usually needed.

**Water**, although often not considered as a nutrient, water is essential to life. The kidneys regulate the water in our bodies and babies need sufficient water from breast or formula milk or as a separate drink, to avoid becoming dehydrated. Babies cry because of thirst as well as hunger, so it is a good idea to offer plain cooled, boiled water between feeds. An adequate fluid intake is also important to avoid constipation. (See also section on "Constipation".)

### **What about breast feeding ?**

Human milk is an unique food perfectly suited to most babies to promote optimal growth and development. It also contains precious antibodies which contribute to the baby's defence against infection. Breast feeding may also lessen the baby's risk of allergy. It is possible to breast feed a baby with EB, provided that the baby grows well. You may need to apply white soft paraffin or Vaseline to the baby's lips and to your nipples to minimise the friction on cheeks, lips and gums which can occur when the baby nuzzles against your breast during rooting and as he suckles. Even if your baby has mouth blisters, this does not necessarily rule out breast feeding.

Here are a few tips which mothers of EB babies have found helpful :-

- Put the baby to the breast often and let him suckle as long as he wishes.
- Allow plenty of time so that neither of you feels rushed.
- If your breasts are very full, express a little milk first so that the baby does not choke when the milk comes down.
- Make sure that the baby is properly latched onto the nipple and not askew.
- Mouth blisters usually burst during suckling. If not, burst them as advised by the EB Nurse Specialist.

If your baby's mouth is too sore for him to suckle, or if he tires easily, you could express your milk and feed it from a dropper or spoon, or a specially-manufactured bottle and teat such as the Haberman Feeder® (Athrodax Healthcare International, Ross-on-Wye, UK). The teat is specially shaped, and is less likely to damage the gums than normal teats, it also contains an internal valve which allows control over the flow of milk, helping a baby with a weak suck to receive a good flow of milk. The nutritional content of your breast milk can be increased in various different ways; the dietitian can discuss which is best for your individual situation.

Alternatively, the hole in a conventional teat can be enlarged using a sterile needle or by making a small cross cut with a pair of sharp scissors. Sterilise the teat before use. Take care that the faster flow of milk does not cause coughing or choking.

### **What if you don't breast feed ?**

Because EB babies often have increased nutritional requirements, breast milk alone may not be enough to promote satisfactory growth. If this is the case, the dietitian will discuss with you the best feeding plan for your baby. It may mean adding nutrients to your expressed breast milk (EBM), giving him some bottle feeds in addition to your breast milk, or it may mean your stopping breast feeding and giving fortified ready-made feeds instead. (See section on "Weight gain and fortified feeds".)

If you choose not to breast feed, for whatever reason, do not feel that you are letting your baby down. He will derive very satisfactory nutrition from one of the baby milk formulas which have been manufactured to resemble human milk as closely as possible.

If your baby is bottle-fed and his mouth is very sore, sucking may be made more comfortable by enlarging the hole in the teat or by using a Haberman Feeder (see previous section). Do this with a needle, or make a small cross-cut with sharp scissors.

### **Weight gain and fortified feeds**

The best gauge of any baby's progress and development is increased weight, length and head circumference and your baby's weight in particular, should be checked regularly to ensure that he is thriving well. This will probably mean weighing on alternate days in hospital, and weekly to start with once he goes home. If possible, this should be done on the same scales and without dressings or clothes. Alternatively, weigh the baby with dressings and at the next bathtime or dressing change, weigh the old dressings and subtract the difference.

If your baby's weight gain is a little slow, the dietitian may advise you to add some extra nutrients to your expressed breast milk and / or to give him one of the commercially-available feeds which are specially formulated to contain a higher concentration of nutrients than regular baby milks. Examples of these include

Nutriprem (Cow & Gate), SMA Low Birthweight Formula (Wyeth), Infatrini (Nutricia) and SMA High Energy (Wyeth). Alternatively, you might be advised to make up his feed in a concentration greater than the usual dilution of one scoop of babymilk powder to 30 ml (1 fluid oz) of water. This will give a feed richer in all nutrients but in the same volume of fluid as before. This is called fortifying the feed. *It is safe, provided that it is done under medical or dietetic supervision and reviewed regularly.*

- An example of such a feed would be :-

4 scoops of babymilk such as SMA Gold (Wyeth) or Premium (Cow & Gate) [the usual dilution is 3 scoops]  
plus 100 ml (3-4 fluid oz) cooled, boiled water.

If your baby needs more energy (calories), this can be provided in the form of a specially manufactured supplement of carbohydrate and/or fat mixed with the babymilk. The most commonly used carbohydrate supplements are called glucose polymers. Brand names include: Caloreen (Nestle), Polycal (Nutricia), Maxijul (Scientific Hospital Supplies) and Polycose (Abbott).

- An example of a feed incorporating a glucose polymer would be :-

4 scoops of babymilk  
plus 1 scoop glucose polymer (using babymilk scoop)  
plus 100ml cooled, boiled water

Calogen (Scientific Hospital Supplies) is the brand name of a fat supplement in the form of an oil and water emulsion.

A combination of glucose polymer and fat is available in two forms, Duocal (a powder), and Liquid Duocal (both (Scientific Hospital Supplies)).

All these energy supplements can be obtained on prescription from your general practitioner (GP). Always ask your dietitian for advice regarding their suitability for your baby, and directions for their use.

*Keep in contact with your dietitian so that she can check the adequacy of your baby's feeds regularly, assess the need for supplements and liaise with your GP.*

### **Fruit juice and other fluids**

Babies do not normally need any fluids other than breast milk/formula milk to nourish them and boiled water to quench any extra thirst. Fruit juices and herbal infusions are not an essential part of a baby's diet and the feeding of a sweet-tasting fluid may suppress the baby's appetite for feeds. Babies often cry because of thirst as well as hunger, so it is a good idea to offer your baby cooled, boiled water in between feeds, especially in hot weather. If he is thirsty, water is the perfect drink.

An inadequate fluid intake can cause and aggravate constipation. If you feel that your baby needs more fluid, but he refuses water, offer ready-to-feed baby juice diluted with an equal amount of water or 1 teaspoon of fresh fruit juice plus 100ml cooled boiled water. (See also section on "Constipation".)

Colic can be caused by swallowing air while feeding, especially if the hole in the teat has been enlarged. Check that the bottle is held so that the contents always fill the teat, and gently wind the baby regularly during feeding, by gently patting his back (do not rub), or rocking him over your knee.

### **Weaning**

Weaning is the process during which babies learn to graduate from sucking to biting, chewing and swallowing progressively more solid foods. Every baby is an individual, and arrives at this stage in his own time, but by three to four months of age he should be ready to try something new. Although the EB baby is no different in this respect, a sore mouth or tongue may mean that he takes considerably longer to become accustomed to changes in flavour and texture.

There are other reasons why an EB baby may be slow to take solids. One of these is a fear of choking on the unfamiliar consistency or flavour. This is more likely to happen if the baby has experienced vomiting or gastro-oesophageal reflux in the past. Gastro-oesophageal reflux is the return of acid, or acidic stomach contents, from the stomach back up the gullet or oesophagus, and it is a very unpleasant and painful experience. It is common in all babies, but in EB babies it is especially important to treat it promptly because of the effect of stomach acid on the delicate lining of the oesophagus. Your specialist can prescribe anti-reflux medication, and you may also be advised by the dietitian to thicken your baby's feeds. Thicker feeds are less likely to reflux back up the oesophagus.

### **Take it slowly**

The important thing is not to rush your baby into taking solids; he will get there in his own time. There is nothing to be gained and much to be lost by trying to make him go faster than he is willing to go. It is highly inadvisable to try to “starve” him into taking solids by withholding some of his milk feeds. This will result in weight loss, and only add to the frustrations and stresses surrounding feeding. Rather, contact your dietitian and she will be able to suggest strategies appropriate for your individual situation.

From the start of weaning and over the next few years, eating habits are established for life. It is very important to set the right foundations by offering foods on which an appropriate diet can be built. Babies and young children learn by copying those around them and are greatly influenced by other people's reactions to foods, their likes and dislikes. Mealtimes should be enjoyable social occasions, so whenever possible, feed your baby in the company of others and make food fun.

Your own nutrition is important too, especially if you are breast feeding. A new baby is very demanding and you will be better able to cope with the less easy days if your health is good. This will depend to a large extent on eating well and trying to fit in some relaxation.

Weaning foods can be introduced to the EB baby in just the same way and at the same time as for other babies. At first, solids should supplement milk feeds, not replace them. If your baby is having one of the more concentrated feeds (see page .....), his appetite for solids may be small. Do not worry if this is the case; as long as you are offering a range of appropriate foods, his nutritional needs will be met.

As your baby gets older, he will eat larger amounts of solids and drink less milk. However, milk will continue to provide a valuable source of nutrients, and he should continue to drink at least 600 ml per day after he has been weaned.

### **What to offer, when and how**

There is a suggested plan for introducing solids at the back of this booklet. Use this as a guide rather than a strict timetable. Let your baby progress at his own pace.

- Weaning solids can be home cooked or commercially prepared.

- Do not cook with, or add salt to home cooked food.
- Ensure that home cooked food is lump-free by pureeing it in a food mill (mouli) or liquidiser, if possible, do not sieve food as this reduces the fibre content.
- Use a spoon especially designed for baby feeding. It can be made of strong plastic or metal and should have no sharp edges.
- Always give solids from a spoon; don't add them to bottles.
- Choose a time of day when your baby is most hungry and when you have most time to relax.
- Offer solids before your baby is too hungry for the next feed. Give some milk feed first to satisfy him if he is crying.
- Begin by offering a little cereal at one feed, eg 1-2 teaspoons of baby rice mixed to a smooth paste with breast / babymilk.
- Do not be disappointed if your baby refuses new foods at first. It takes time to get used to new flavours and textures.
- Gradually increase solids according to your baby's appetite by offering cereal or pureed fruit or vegetable (apple, pear, carrot) at a second feed.
- After about three weeks, introduce pureed meat or Stage 1 commercial savoury babymeals.
- Between 6 and 9 months, babies gradually learn to chew, and foods need to be more lumpy. Fruit and vegetables should be mashed, meat minced or Stage 2 or Junior foods given.
- Finger foods should be encouraged now, even if your baby has dressings on his hands. Babies need to touch food and feed themselves even if it is a messy business and means an extra quick dressing change! Do not give sharp or rough foods which may scratch the mouth and gums - try rusks which melt in the mouth eg. Farleys, also ripe banana, soft pear or peach, cooked carrot, potato, swede. Never leave a baby alone to eat in case he chokes.

### **When can cows' milk be introduced ?**

Ideally, all babies should receive either breast milk or an infant formula until one year of age. Many non-EB babies are switched to cows' milk at about six months. However, EB babies with their higher requirements should continue to take the recommended infant formula, fortified if necessary (see section on "Weight gain and fortified feeds"), for at least the first year and possibly longer. A "follow-on" milk, designed to bridge the gap between infant formula and cows' milk may be suitable after 6 months. Skimmed and semi-skimmed milks are generally unsuitable because they are low in fat and therefore low in energy.

Yoghurt and fromage frais made from pasteurised cows' milk may be given from about nine months. Choose the full fat, sugar-containing varieties of these products as the energy content is higher than the low calorie types.

### **Towards the end of the first year**

By 9-12 months, many family meals can be suitable for the EB baby, provided that they are of an appropriate consistency and not too spicy. Citrus fruits, eg oranges or tangerines, tomatoes or sharp fruit juices may cause discomfort if the mouth is blistered, cool foods may be more acceptable at such times. Foods which are likely to cut or scratch and blister the mouth or throat should be avoided eg. crisps, hard crusts and sharp chips, toast, crackers etc. If you give fish, check very carefully that all bones have been removed. Be careful with hard pieces of fruit eg. apple which may cause choking.

Encourage a good, balanced diet with the emphasis on protein and energy. If your child has a small appetite, offer three small meals a day with nutritious snacks between meals. Milk continues to be an important source of many nutrients, so do not give less than one pint (600ml) daily of the recommended milk formula. Many babies prefer to take milk from a bottle rather than a cup or teacher beaker. By all means, try to wean off the bottle but don't force the issue if it risks a significant reduction in milk intake.

### **Can't eat, won't eat ?**

During the forthcoming months, normal events such as teething, minor illness and food fads will interfere with feeding. These are all part of normal development, but to parents who appreciate the importance of nutrition, they can be difficult times. Children rapidly pick up parental worries about feeding, so if your child is having an "off day", try not to transmit your anxiety and never force-feed.

A well-nourished child will be better able to cope with periods of poor food intake, so gradually accustom your child to extra protein and energy in his diet as routine, rather than waiting until an episode of poor eating when they are less likely to be accepted. Add extra protein and energy to the diet in any of the following ways :-

- Add 2-3 teaspoons cream or evaporated milk to mashed potato, sauce, yoghurts, custard, mousse, jelly. (Single / whipping cream or evaporated milk can be frozen in ice cube trays for later use.)
- Add a knob of butter or margarine to hot vegetables.
- Spread butter, margarine, cream cheese or smooth nut butter liberally on bread, soft toast and plain sweet and savoury biscuits.
- Add grated cheese / cream cheese / mayonnaise to mashed potato, baked beans, spaghetti and scrambled eggs.
- Serve white or cheese sauce with fish and vegetables.
- Offer ripe avocado pear either mashed or as a finger food.
- Add 1-2 teaspoons of jam, honey or lemon curd to custard and rice pudding.
- Add 1-2 teaspoons of sugar to breakfast cereals, yoghurts, stewed fruits.
- Top bread or biscuits with jam, honey, lemon cheese or chocolate spread. Mix any of these spreads into milk puddings or yoghurt.
- If your child requires a pureed diet, use soup, milk or white sauce to mix with it. Water will dilute the food making it taste bland and reducing the nutrient content. Try not to sieve pureed food as this reduces the fibre content.

## Constipation

Constipation in babies and young children is often the result of an inadequate fluid intake, due to a reduced intake of feeds and/or increased requirements in hot weather. An EB baby with extensive blistering may have fluid requirements considerably above normal. Constipation can be aggravated by iron supplements. It may also occur for no apparent reason.

The frequency with which the bowels are opened is less important than the degree of discomfort felt. Provided the motions are soft and painlessly passed, it is not essential that the bowels are opened every day.

For an EB baby, straining to pass even a moderately bulky motion may cause pain and blistering of the delicate skin around the anus. Fear of pain on passing further motions can quickly lead to withholding the motion and before long a vicious cycle is set up as he becomes more constipated and appetite is reduced. Because regular bowel movements also depend on a regular intake of food, a poor appetite and irregular feeds can lead to harder, drier motions.

The importance of preventing constipation cannot be overstated. Try to ensure a generous fluid intake ie. at least 150ml per kg (2-3oz per lb) per 24 hours, for young babies who are not receiving fluid from foods. If your baby refuses plain cooled, boiled water, offer well-diluted fresh fruit juice (ie 1 teaspoon juice diluted with 100 ml water) or give ready-to-feed baby juice diluted with an equal volume of water. If extra fluid makes no difference to the constipation, try adding a teaspoonful of sugar to all babyfeeds for several days. Alternatively, try giving the diluted juice from a tin of prunes or the water in which dried prunes have been stewed.

Once your baby is taking solids, try to include fruit and vegetable puree daily. From about 9 months, offer wholegrain cereals such as Weetabix, and from 10-12 months, include baked beans and sweetcorn. The fibre in these foods, combined with an adequate fluid (about 100ml per kg, 1-2oz per lb) will help to keep the stools soft and they will be more comfortably passed. (See earlier section on fibre.) Your dietitian can advise on suitable pure fibre sources. **Unprocessed bran should not be given.**

If constipation persists despite these measures, a gentle laxative may be required. It is important to give this regularly as a preventative measure rather than waiting until he is very constipated. Ask for specialist advice about this.

## **Sugar and tooth care**

Dental caries or tooth decay occurs when bacteria in the plaque around the teeth react with the sugars in food to produce acid. The acid dissolves the tooth enamel and the resulting caries may cause pain and teeth may need to be filled or extracted.

Sugar is present as an ingredient in many foods as well as in the sugar bowl. The number of times sugar-containing foods or drinks are taken is as important as the overall amount consumed. Sugar at mealtimes seems to be less damaging to teeth than sugar taken on its own; eg. a bar of chocolate or a sticky bun eaten with a savoury snack or main meal is less harmful than the same foods eaten on their own.

The teeth of EB sufferers can decay partly due to the structure of the teeth, but mainly because blistering and scarring of the tongue can reduce its ability to cleanse the teeth in the normal way. Also, it is recognised that many EB sufferers need high energy intakes and this often cannot be achieved without the consumption of considerable amounts of sugar and frequent meals and snacks.

Compromise is possible and if sugar is used sensibly, its benefits as a high energy food can be exploited, whilst at the same time minimising the likelihood of tooth decay. Here are a few important points :-

- Babies should not normally have sugar or syrups eg rose hip syrup, Ribena or fruit squash added to their bottles and dinky feeders should never contain anything other than plain boiled water.
- Dummies are usually inappropriate because of the danger of blister formation, but if used, they should never be dipped in honey, jam or sugar.
- Suitable drinks are water, babymilk, cows' milk, and diluted fresh fruit juice. Tea and coffee are unsuitable for babies. Lemonade, coca cola, cordial squash etc. should be avoided because of their sugar and acid content both of which are harmful to teeth.
- For snacks, try to give cheese; sandwiches filled with smooth nut butter, Marmite, cheese spread or meat/fish paste; or savoury biscuits which melt in the mouth.
- It is unwise to give sweets and foods with a high sugar content (eg. chocolate

biscuits) to babies under one year as this may encourage a liking for these foods to the exclusion of more nutritious items. If they are offered, they should always be restricted to mealtimes when the presence of other foods in the mouth partly neutralises the acid produced.

- It is better to finish a meal with a savoury rather than a sweet food.
- Even young children with only one or two teeth should see a dentist, preferably one familiar with EB. Good dental hygiene is essential and the dentist can give advice on appropriate cleaning techniques, mouthwashes, fluoride supplements etc.

### **Acknowledgement**

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