I N F O R M A T I O N

CYSTIC FIBROSIS TRUST

NUTRITION

Eating well with Cystic Fibrosis. A guide for feeding infants

Cystic Fibrosis Research Trust registered as a National Charity in Great Britain No. 281287

Contents

This booklet isn't intended to replace a specialist. It is designed to help you when you consult your GP, doctors or speak to the staff at your local clinic.

Published by the Cystic Fibrosis Trust assisted by Anita MacDonald and Carolyn Patchell of the Dietetic Department, Diana, Princess of Wales Hospital Birmingham.

Published with the generous support of

SHS INTERNATIONAL

February 2000

A guide to feeding infants

CYSTIC FIBROSIS TRUST

Feeding a baby with Cystic Fibrosis is similar to feeding any other baby. However, babies with Cystic Fibrosis do have some additional needs. These are:

- Most need pancreatic enzymes with feeds. These will replace the enzymes normally produced by the pancreas and help breakdown the starches, proteins and fats found in milk and solid foods.
- Some need extra calories to help them gain weight and grow to their full potential.
- All need extra A, D and E vitamins.

Giving of pancreatic enzymes with all meals

Breast and normal baby milks are both suitable for most babies with Cystic Fibrosis. However, sometimes these milks need slight modification to achieve the required weight gain.

The dietitian and doctor will discuss with you the best type of milk to use for your baby. However, the following information gives some background to the different options available.

Which milk should I feed my baby?

CYSTIC FIBROSIS TRUST

Normal baby milks

Breast Milk

Breast milk is the best milk for babies without medical problems and it is also suitable for babies with Cystic Fibrosis. It contains everything needed for growth and development during the first four months of life. The nutrients it contains are easily digested and absorbed. In addition, it contains antibodies which offer some protection against certain infections, such as coughs and colds, ear infections and tummy upsets. Research shows that babies with Cystic Fibrosis grow well on breast milk and it should be encouraged wherever possible.

However, occasionally, babies may have difficulty gaining weight because of their extra calorie needs. If this is the case and the breast feeding technique (ie attachment and positioning on the breast) is good and frequent feeds are being given, then it may be necessary to consider giving extra calorie supplements added to a little expressed breast milk. Advice will be given by your dietitian or doctor if this is appropriate.

Normal Baby Milk

There are a large number of normal baby milks available which are designed for between 0-12 months old. They are all suitable for babies with Cystic Fibrosis and most babies will gain weight satisfactorily on these.

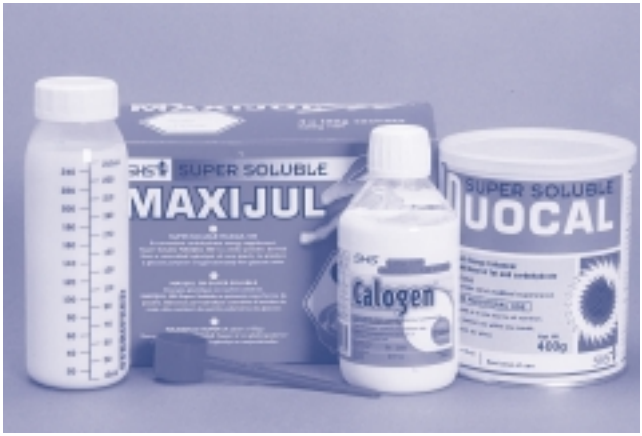
Supplementing Normal Baby Milks

Sometimes babies do not gain weight on normal baby milk. It is therefore necessary to add extra calories to the baby milk. Your dietitian may do this in one of two ways.

1. Add calorie supplements to the baby milk. This may be in the form of adding either:

- a combined fat/carbohydrate powder (ie *Duocal* – SHS) to the baby milk
- a separate carbohydrate powder (eg *Maxijul* – SHS, *Polycal* – Nutricia, *Caloreen* – Nestlé, *Polycose* – Ross) and fat mixture (eg *Calogen* – SHS) to the baby milk.

2. By concentrating the baby milk, by adding slightly more baby milk powder to each bottle.



Extra calorie supplements to normal baby milk to assist weight gain

Caution

Supplementation of normal baby milk is a process which should be done very carefully to ensure the correct quantity of extra powder and liquid is added. If the feed is made up too concentrated it may cause diarrhoea and vomiting. It should always be done under the supervision of a dietitian who will give clear instructions on what to do.

High Calorie Baby Milks

High energy formula

A simpler alternative to adding calorie supplements is to use the new high calorie baby milks which already contain extra calories and other nutrients eg SMA High Energy (SMA Nutrition) or Infatrini (Nutricia). They are specially produced for babies who have poor growth and weight gain. They contain more nutrients, are more hygienic and are more convenient than adding calorie supplements. They are available on prescription from your GP. Your dietitian will recommend this type of milk if it is necessary for your baby.

Special Milks

Occasionally, a dietitian or doctor may recommend a special milk which does not contain milk sugar (eg Pregestimil – Mead Johnson, Peptijunior – Cow & Gate). This is because some babies with CF may have a temporary intolerance to milk sugar following surgery for a *meconium ileus* (a bowel blockage which occurs in a small number of babies with CF). However, most babies who have presented with *meconium ileus* should be able to tolerate breast or normal baby milk.

How much milk should babies take?

There are no set rules on this. It is best to feed babies on demand and they will usually take adequate milk. However, if your baby is only taking small quantities of milk or does not wake for feeds during the day, please discuss this with your dietitian. If you have any concerns about the quantity of feed to offer, your dietitian will be happy to give you specific advice.

When can cow's milk be given as a drink?

Pasteurised cow's milk should not be given as a drink before one year as it is low in iron. It is therefore better to continue breast or baby milk until this time. For some babies, there may be advantages in continuing baby milk beyond one year. It contains the same calories as pasteurised cow's milk, but is a good source of many other nutrients including iron and vitamin C. This may be beneficial if a young child is only eating a small quantity of solid food.

Alternatively, from 6 months, follow-on milk can be given [eg *Step-Up* (Cow & Gate); *Progress* (SMA Nutrition)]. They contain more iron and other nutrients, but still have the same quantity of calories as normal baby milks. Unfortunately follow-on milk is not available free of charge on milk tokens for families on income support.

Weaning is the process of gradually adding solids into a baby's diet. It is usually recommended from about 4 months old and there should be no need to give solids earlier than this for the majority of babies with Cystic Fibrosis.

CYSTIC FIBROSIS TRUST

When should weaning start?

Signs which indicate that it is time to give solids include: babies still being hungry after finishing a good milk feed, demanding more frequent feeds and waking in the night for feeds – even though they have previously slept through.

Caution

If solids are started early they should not decrease the volume of milk taken. In the early stages, solids are given to supplement milk intake; not replace it.

Which solids are suitable?

The type of solids given should be similar to the ones given for all babies.

The weaning process is broken down into 3 stages:

- 4-6 months
- 7-9 months and
- 10-12 months.

Information about the consistency, and examples of suitable food to offer babies with Cystic Fibrosis is given for each stage.

continued

First Stage: 4 - 6 months

Consistency

- Foods should be pureed and smooth.

Quantity

- Start by adding 1-2 teaspoons of solids at one milk feed per day. Increase the frequency to twice and then three times daily. Gradually increase the quantity of solids offered, although the amount taken will vary from baby to baby.

Suitable Foods

- Baby rice mixed with breast or baby milk
- Fruit or vegetable puree. Mix with breast or baby milk to boost nutrient content. Try mixing fruit puree with baby cereal.
- Purees of meat and poultry with potatoes and vegetables.
- Pureed potato or sweet potato mixed with other vegetables. Add a cheese based sauce to increase nutrient content.
- Custard (made with cow's milk), full-fat yoghurt, fromage frais.
- Commercial baby foods suitable from 4 months. If using powdered baby foods, make them up with breast or baby milk, even if it states use water on the pack. This will boost the nutrient content.

Second Stage: 7 - 9 months

Consistency

- Foods should be mashed or minced. Begin to give finger foods. Try offering some milk feeds from a feeder cup.

Quantity

- Feed to appetite, However, babies should be on solids three times a day. Try and give 500-600 ml (1 pt) daily of milk.

Suitable Foods

- Minced meat, chicken or fish.
- Mashed potato or sweet potato with added margarine/butter and milk.
- Mashed cooked lentils with rice.
- Scrambled egg with plenty of milk, margarine/butter and milk – give with fingers of toast.
- Mashed vegetable with white or cheese sauce eg cauliflower cheese.
- Cooked fruit with fromage frais, yoghurt or custard.
- Instant oat cereal or Weetabix with milk and a little sugar.
- Commercial baby foods suitable from 7 months. Make up powdered baby foods with milk rather than water.

Suitable Finger Foods

- *Fingers of toast with margarine/butter and jam.*
- *Chapatti/pitta bread with margarine/butter.*
- *Breadsticks – dipped in margarine/butter.*
- *Cheese cubes or fingers.*
- *Banana, melon or apple slices.*
- *Baby rusks (not low sugar).*
- *N.B. Babies should always be supervised while eating finger foods.*

continued

Third Stage: 10 - 12 months

Consistency

- Foods should be chopped or minced.

Quantity

- Feed to appetite. Offer 3 times daily. Still try and give 500-600 ml (1pt) daily of milk.

Suitable Foods

- Minced meat, chicken or fish.
- Chopped sausage or fish fingers.
- Mashed pasta with cheese or meat sauce.
- Boiled egg with toast and butter/margarine.
- Shepherds pie (with extra milk and butter added to potato) and baked beans.
- Mild vegetable curry with chapatti or rice.
- Fruit crumble and custard.
- Sponge and custard.
- Mousse or blancmange.

CYSTIC FIBROSIS TRUST

Your Questions

Well diluted fruit juice or baby juice may replace an infant feed at meal times

What about drinks other than milk?

Until 4 months of age, milk is the only drink that most babies need, although in hot weather some need a little extra cooled boiled water.

From about six months, water, well diluted fruit juice or baby juice may replace an infant feed at a mealtime, but it is important to maintain a milk intake of 500 ml-600 ml (1pt) in babies over 6 months. This can be offered from a feeding cup at this stage.

What about vitamin supplements?

In CF, there is usually some loss of vitamins A, D and E in the stools. It is important to give your baby additional supplements of these.

Vitamins A & D are usually given together in a liquid medicine which contains other vitamins such as the B and C group. (eg *Abidec* –Parke-Davis Medical, *Dalivit* – Eastern Pharmaceuticals).

Vitamin E is given as a separate liquid preparation.

Caution

There is no need to give the routine Mother and Children vitamin drops in addition to these vitamin supplements.
You should discuss any additional supplements with your dietitian/doctor.

How are pancreatic enzymes given?

Most babies with Cystic Fibrosis will need pancreatic enzymes. The dose will be prescribed at the hospital clinic and will vary from baby to baby. For both breast and bottle fed babies, it is best to mix the microspheres with a little fruit puree and give from a spoon at the beginning of the feed. Either home-made fruit puree or any of the commercial baby fruit desserts are suitable.

Caution

Do not place the dry granules into a baby's mouth or it may cause the baby to choke.

It is best to mix the microspheres with a little fruit puree and give from a spoon at the beginning of the feed

This will hold the granules into a gel and make them easier for the baby to swallow.

Is additional salt needed for babies?

Breast or baby milks are very low in salt and occasionally this may cause problems for CF babies. Some doctors give babies extra salt in the form of a salt solution that is made up by chemists and is available on prescription from GPs.

If your baby needs an extra salt supplement, your doctor will recommend this.

Caution
Please do not add extra salt to expressed breast milk or bottle milk without advice from your doctor. *Adding too much salt to a baby's feed can cause vomiting and kidney problems.*

CYSTIC FIBROSIS TRUST

Conclusion

Feeding a baby with CF should not be too different from feeding any other baby. It does require extra time and effort to give the pancreatic enzymes and perhaps prepare baby milk, but if a good routine is developed, these extra tasks should soon become second nature.

At times, it can be frustrating to feed any baby; but equally it can be good fun for both parents and babies.

Please try and enjoy this experience and remember your dietitian or staff at the CF clinic will be happy to help with any queries you have about feeding.

If a good routine is developed, extra tasks will become second nature.

Further enquiries about literature, including booklets produced by the Association of CF Adults, and donations should be sent to

Cystic Fibrosis Trust
11 London Road
Bromley
Kent BR1 1BY

Tel: 020 8464 7211
Fax: 020 8313 0472

enquiries@cftrust.org.uk

www.cftrust.org.uk

Publications

AUDIO TAPES

Finding out about cystic fibrosis
A guide for parents and other relatives of newly-diagnosed children.

Growing up with cystic fibrosis
Advice and information for 12-16 year olds with CF and those who care for them. Useful for brothers, sisters and friends too.

Living with cystic fibrosis
Adults discuss some of the challenges of living with CF.

Cystic fibrosis and school
Advice for teachers, parents and people with CF starting or changing schools.

† **Diagnosis** A guide for parents and other relatives of newly-diagnosed children in the Asian community.

† **Adolescence** Information for Asian families about growing up with CF.

† *These tapes are available in Urdu and Gujarati only.*

THE FACTS
An introduction to the causes and effects of Cystic Fibrosis.

GENETICS
Genetics, carrier tests and tests during pregnancy

A PATIENTS' CHARTER
The care of patients with Cystic Fibrosis. Describes the essential health care people with CF should expect. Drawn up by directors of specialist UK CF Centres in the UK with 50 or more patients.

FINDING OUT
A guide for parents of newly diagnosed children with Cystic Fibrosis.

NUTRITION
Eating well with Cystic Fibrosis – A guide for feeding infants (from birth to one year of age).

CYSTIC FIBROSIS AND YOU
For children up to the age of about 12.

NUTRITION
Eating well with Cystic Fibrosis – A guide for children and parents (from age one to 16 years).

CYSTIC FIBROSIS AND SCHOOL
A guide for teachers and parents of children with CF starting or changing school.

GROWING UP
A guide for young people with Cystic Fibrosis (12 to 18 year olds).

TRANSITION
A guide for young people moving from paediatric to adult care.

NUTRITION
Eating well with Cystic Fibrosis – A guide for adults.

TREATMENT
Physiotherapy for Cystic Fibrosis. Illustrates all methods of physiotherapy in CF.

TREATMENT
Home Intravenous Therapy and Cystic Fibrosis. A guide for patients, parents and carers.

DIABETES MELLITUS AND CYSTIC FIBROSIS
Describes the incidence and combined treatment.

TRANSPLANTS
Lung and heart-lung transplantation for patients with Cystic Fibrosis.

SUPPORT SERVICE
Outlines the help available from the Cystic Fibrosis Trust Support Service.