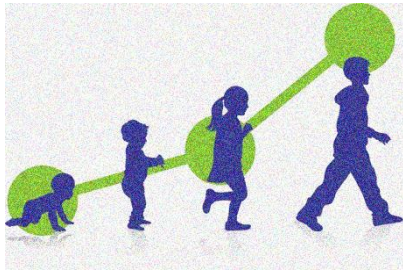




**NUTRITION BOOKLET FOR
FAMILIES OF PATIENTS WITH
INTERSTITIAL LUNG DISEASE
(chILD)**

**Prepared by:
Prof Dr Nural Kiper
Associate Prof Dr Nagehan Emiralioglu**

Supported by COST Action CA 16125



Why is Nutrition Important?

During childhood, infants and children are growing and developing their bodies and minds at an incredible rate. Proper nutrition and caloric intake is important to keep all children on track for a healthy future. For a child to grow normally, they must consume enough calories to fuel their bodies need for daily activities, plus what they need for their growth and development. For infants and children with any form of Interstitial Lung Disease, this can be a challenge. When children work harder to breathe, they burn more calories and so proper nutrition is especially important. Also, because their breathing is harder, it can make it difficult to eat and swallow normally. As a caregiver, it is important to understand the issues and work with the right specialists, so your child has the best chance for growth and development.

Interstitial Lung Disease (ChILD) Nutrition

Slow growth and weight gain are common problems in children with interstitial lung disease. Children with interstitial lung disease need high calories because they breathe frequently (to provide oxygen). The harder they work to breathe, the more calories they need. So, it is important to manage both pulmonary function and nutrition as a part of their overall treatment plan. If weight gain and growth is good, the child will develop in accordance with their peers. On the other hand, **weight loss and slow growth** are concerning and should be consulted for support to treat the underlying cause. Early intervention helps children improve their quality of life and reduce the impact of your child's lung disease.



Keeping Track of growth and nutrition takes a team effort!

Let's face it. Your child's doctors only see a small part of your child's day-to-day life. So it is important to work together to track weight and growth, and to identify any feeding issues early.

Caregivers and parents can look for early indicators of feeding issues to identify problems before growth becomes an issue. At home, caregivers should watch for any difficulties with eating and drinking, especially during times when your child is sick or breathing hard. Babies with rapid breathing problems may also have problems with sucking and swallowing. Both breathing and feeding can be difficult together.

Signs of your infant or young child, which may indicate difficulty eating:

- Babies that have to take frequent breaks during breast feeding or a bottle to catch their breath.
- Infants or children that make a choking sound or cough when they take a drink (or soon after).
- All infants occasionally spit up or have reflux after eating. However, infants and children with excessive vomiting or spit up should be of concern.



If your child is experiencing such signs, these should be discussed with your doctor. Since sometimes healthy children also behave alike, it can help to record the frequency over a period of time to identify patterns and give the doctors clues to the extent of the problem. It can sometimes be helpful to take a short video of what you are seeing to share with the doctor, especially if the problem is happening during an activity that can't be seen in a doctor's office. As a part of their routine care, body weight and height of all children with interstitial lung disease should be regularly monitored at intervals of one to three months and recorded on growth cards. Inadequate weight gain and short stature usually indicate that the child is getting less calories than necessary, and a doctor and dietician support is needed to calculate the required calorie intake.

Other measurements that can help assess nutrition and daily needs are the measurement of height, body weight, head circumference under 2 years of age, determination of daily calories and protein needs in his diet and review of eating problems with the dietician.



A recorded food diary of the child's daily nutritional intake can help, and thus the daily caloric intake can be calculated. If their caloric intake is too low, they will probably need a supplementary high-calorie drink or other nutritional support, to make sure they have enough to grow and develop. Most doctors and dieticians have examples of these diaries and there are easy apps that can help you do this at home.

Infant Nutrition



Breast milk is the best calorie source for infants because it is easily digestible, nutritionally complete, and also contains immune support from the mother that can help infants to fight infection.

Whenever possible, breast milk should be the primary food source during the first 6 months. However, infants receiving breast milk may need additional calories due to illness or may need to have the milk thickened and fed with a bottle. If breastfeeding is not an option, additional support may be needed to increase calorie intake when using formula foods. Your baby should be monitored at regular intervals and recorded on growth cards until he/she is two years old.

Child Nutrition



As your child gets older, monitoring their nutrition is still an important part of their overall care. The amount of food and nutrients they eat along with their growth should be closely monitored and adjusted as needed. Working with a dietician and creating regular

meal plans and snacks can help a lot. It is important to make eating a positive experience and encourage your child to eat what you give them.

You should offer a balanced diet of different foods and allow your child to make their own choices. When high caloric requirements are needed, your pediatrician and dietician will help you find out what foods to eat and how much supplemental products you can give. If your child refuses to eat some types of foods, your

dietician can suggest alternate foods or ways to serve them to keep a well-rounded diet.

So what happens if my child needs more help with nutrition?

If any problems with eating or poor growth are observed by a doctor or a child's caregiver, your doctor and dietitian should be consulted to evaluate the problem and help you to provide adequate nutrition. Blood tests may be considered when you are admitted to hospital. If your child has a history of aspiration, a swallow study should be performed.

What is gastroesophageal reflux?

During feeding, food passes from the mouth to the esophagus and from there to the stomach. Once the food passes into the stomach, it normally stays there until it moves farther down the digestive system. However, sometimes the solid foods or liquids escape back up into the esophagus. When this occurs, it is known as **gastroesophageal reflux**. Reflux is common in infants but can become a problem in children with interstitial lung disease if not identified early. When reflux causes a decrease in weight gain and respiratory symptoms, nutritional recommendations should be made, feeding positions should be recommended and medication should be given if it is indicated. In some cases, reflux can be reduced by the use of thickening supplements added to nutrients. Although rare, surgery may be necessary in some cases.

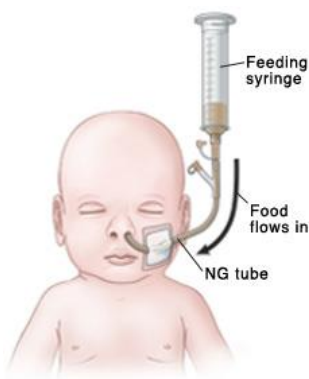
Nutrition Tubes

If oral nutrition is not adequate to sustain growth, your doctor may recommend a feeding tube that can deliver high calorie, nutritious liquids

directly to the stomach. These can be a temporary solution to support a child through an illness or until their pulmonary symptoms are improved. But for some patients with severe gastroesophageal reflux, chewing or swallowing problems, or severe lung disease, these may be permanent. While a tube may seem drastic, there can be advantages for the patient:

-
- Feeding tubes can provide concentrated nutrition for children that are too tired to eat, have a food aversion, or have difficulties swallowing. Whenever possible, food should still be offered orally and the child should participate in family meals, but a tube can take the burden off the child and caregiver to make sure they eat enough.
 - Some drugs can be delivered through these tubes but the placement of the tube and the type of medication may not work well. Please check with your doctor before giving a medication through the tube.
-

If your doctor recommends a feeding tube, there are a couple of options to consider. There are two main ways of inserting these tubes: nasogastric and percutaneous endoscopic gastrostomy (PEG).



Nasogastric tube

The nasogastric tubing is a soft, thin plastic tubing that runs from the nose to the esophagus, through the stomach, and is attached to the cheek with a patch.

Children usually get used to this tube in a short period of time and these tubes do not interfere with normal

eating. These feeding tubes are replaced every 3-6 weeks and can be replaced at home with a little training and practice.

The daily supplementary nutrients supplied by the nasogastric tubing can be delivered several times at a time or for several hours with a special pump. A disadvantage with nasogastric tube is that they can be easily and involuntarily removed by children. This can cause a more serious problem of food or fluid leakage to the lungs if the tube is removed during nasogastric feeding. Therefore, the child should only receive nasogastric nutrition while in the observation of their relatives.

Percutaneous Endoscopic Gastrostomy (PEG) Tube



For patients that will need nutritional support for longer periods or do not tolerate a nasogastric tube, percutaneous endoscopic gastrostomy (PEG) tubes are another option. PEG tubes can be inserted directly into the stomach with a small incision from the upper left quarter of the abdomen. Internal placement of the tubing is performed endoscopically and requires general anesthesia.

Once the tube is placed, the PEG placement site will need some care, but after it heals from placement there is little or no pain associated with having the tube. Children feeding with PEG should be encouraged to continue eating independently and not to give up normal food. Finally, PEG can be easily removed by anesthesia when it is no longer needed.

Acknowledgement:

We thank members of the European Lung Foundation's ChILD patient advisory group for their contributions.