



From parents to parents

FEEDING DIFFICULTIES

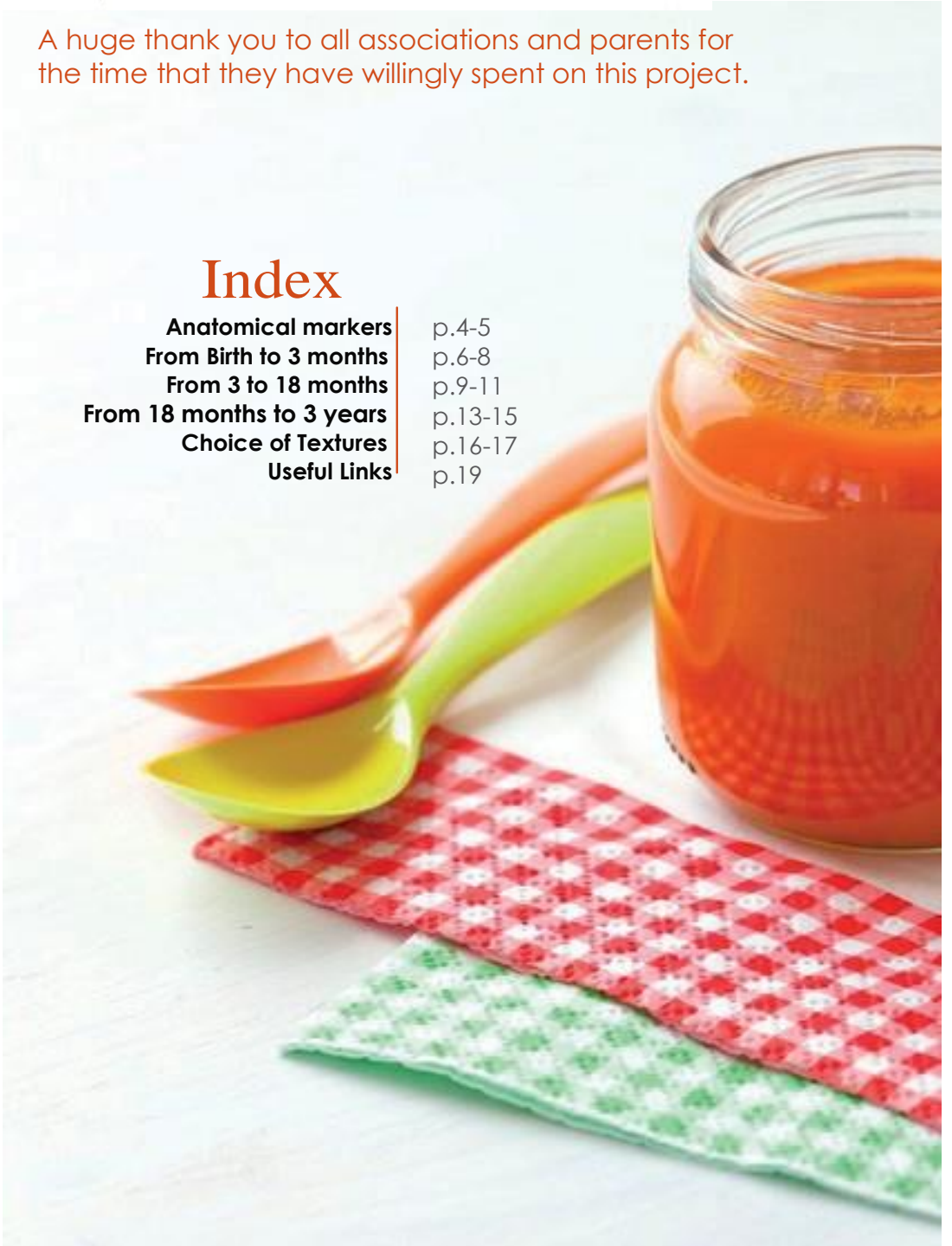
in children between the ages of
0 and 3 years who have a
genetic condition

**Advice
and Tips**

A huge thank you to all associations and parents for the time that they have willingly spent on this project.

Index

Anatomical markers	p.4-5
From Birth to 3 months	p.6-8
From 3 to 18 months	p.9-11
From 18 months to 3 years	p.13-15
Choice of Textures	p.16-17
Useful Links	p.19



A glass of orange juice is visible on the left side of the page, partially obscured by the text box. The background features a red and white checkered tablecloth.

OBJECTIVES OF THIS BOOKLET

In small children presenting with a genetic syndrome, feeding is not always easy. Sucking, swallowing and chewing problems can all disrupt the ability of the child to eat and thus take away the ability to find pleasure in eating. It is important to prevent or manage these difficulties from birth as they can have an impact on the development of oral abilities, both nutritional and verbal.

This booklet has been prepared from testimonials from parents like you who have been concerned about the oral development of their child. It contains answers to common questions, tips from parents and advice from speech therapists.

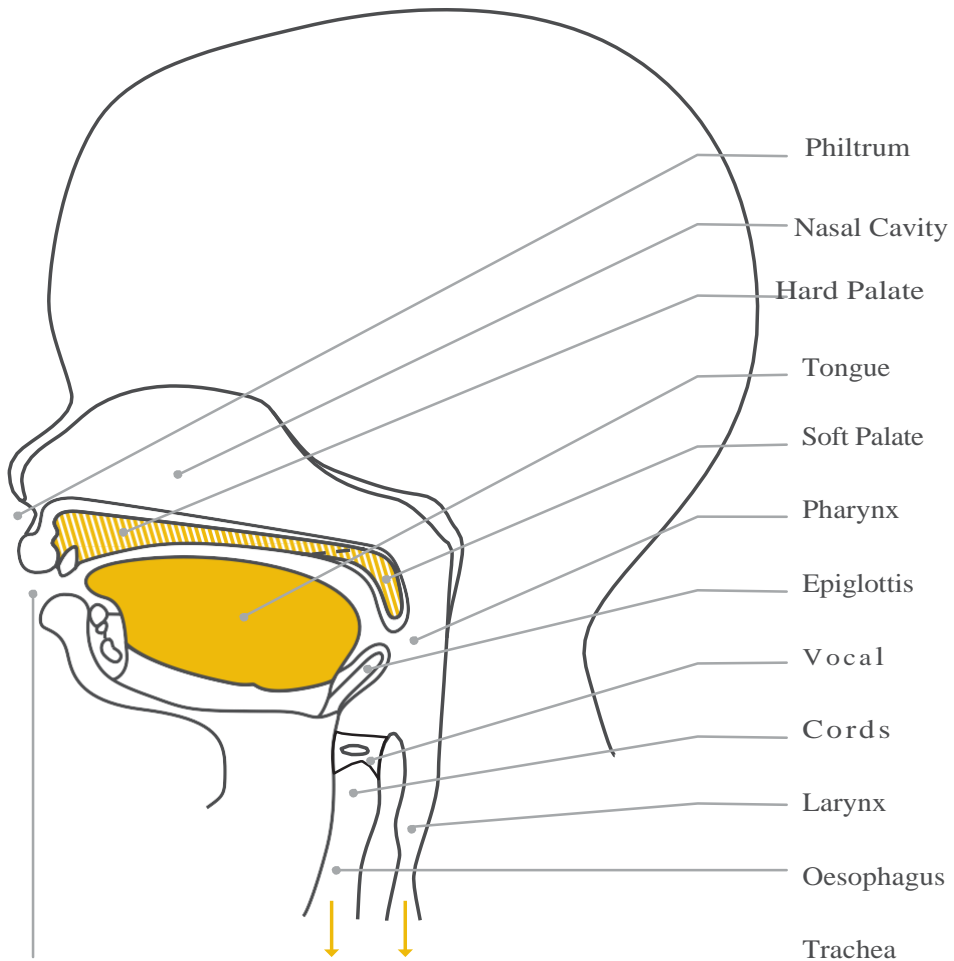
This booklet is here to back you up on a day to day basis, like a toolbox, but it is not a substitute for medical advice.

The advice contained here is not exhaustive; don't hesitate to find your own way. **Trust yourself to know what is good for your child. The most important thing is to be able to, beyond the difficulties, share moments of pleasure and discovery with your child.**

The Orofacial Sphere

Some Anatomical Markers

The orofacial sphere is the term describing the anatomical structures that allow your child to eat, shout, speak, breathe, smile, cry and make faces... These few notions of anatomy will be useful to you in understanding the problems affecting your child.



Lips

Lungs Stomach

Swallowing

The process of swallowing facilitates the passage of food from the mouth to the stomach. It is a succession of complex stages, all interdependent.

■ TIME IN THE MOUTH:

In very little children, the lips tighten on the breast or the teat in an airtight way to push the milk out, suck it in and propel it, thanks to the movement of the tongue, towards the pharynx.

In older children the food is chomped and chewed, together with saliva, to create a "bolus" or food mass. The lips are closed, the tongue rises; the bolus is compressed against the palate and progressively drawn to the back of the mouth. It is then propelled into the pharynx.

■ PHARYNGEAL TIME:

This stage starts with the swallowing reflex. The bolus is propelled towards the oesophagus whilst the airways are protected by various mechanisms.

■ TIME IN THE OESOPHAGUS:

The bolus follows the oesophagus before arriving in the stomach. It is the start of the digestive process.

Wrong Paths

"Swallowing the wrong way" means that saliva or the bolus is propelled through the trachea to the lungs and not to the oesophagus towards the stomach. If these wrong paths are too frequent they can create pulmonary infections. When food is stuck in the trachea the coughing reflex will expel it.

The Soft Palate

The soft palate deserves special attention.

Made up of muscles, it follows on from the hard palate and intervenes in swallowing, hearing and speech. Its contraction makes it rise, allowing the separation of the mouth from the nose.

In children presenting with a genetic syndrome, in particular in cases of split palates, problems such as nasal reflux of food, seromucous ear infections, and poor pronunciation of sounds can frequently occur and are important to spot and take into account. It is therefore necessary to improve the strength of the muscles of the palate veil with games involving blowing air. (See page 15).

Think of consulting with an Ear, Nose and Throat Consultant, especially in winter! Seromucous infections are not painful but can result in loss of hearing.

Little Tip: if your child is frequently scratching his ears, he probably has an infection.

From 0 to 3 Months

In the womb the foetus practices sucking and swallowing. He swallows amniotic fluid and sucks his fingers or his toes. This dual process of sucking and swallowing must be operational at birth for the baby to be able to feed.



From the breast or the bottle efficient suction consists of the following stages:

- The baby's lips are hermetically sealed around the nipple of the breast or the teat of the bottle
- The tongue moves to and fro creating a void in the bucal cavity
- The cheeks contract and the jaw clenches
- The tongue presses on the nipple of the breast or the teat of the bottle forcing milk to spray out.

Your child may encounter problems at one or more of these stages.



Favour skin to skin contact with your baby as much as possible during feeding. In addition to the tender feeling generated, your skin and smell will stimulate the sucking reflex of your baby.

Breastfeeding

A breastfeeding advisor or midwife can help you with any issues

Posture Advice

- **To help your baby to hold the breast in his mouth**, hold your breast with the thumb above and all the other fingers below. As soon as your baby is taking the breast, move your thumb and index in order to hold the jaw of the baby and keep his mouth on your breast (your two fingers will form a “U” shape with the chin of the baby at the base of the “U”).
- **Using a Lactation Aid Device (LAD)** will allow a child with insufficient sucking reflex to stimulate milk production, to be on the breast whilst receiving milk in the mouth via a small tube. This device, that you can make yourself, can also be hooked onto a finger. (See Useful Links).

Breast feeding time can be long and tiring for both you and your baby. Take frequent rests and favour demand feeding. Don't worry about your baby's weight gain – the medical team is there to take care of that.

Bottle Feeding

You can bottle feed your baby using your own milk or by using a breast milk pump, hand operated or automatic, which you can buy or hire in a chemist. Alternatively you can bottle feed your child with baby formula as recommended by your doctor.

Posture Advice

- **Sit with your baby on your knees facing you or to one side slightly upright.** Stroke his philtrum with the teat, and then give him the bottle, holding it more or less horizontally, so that he can suck the milk in the teat **at his own rhythm.**
- If your child has a cleft palate, you can place your thumb on his top lip to assist his sucking.

Choice of Teats

- If your child is having difficulty sucking, **favour soft teats:** you can put rubber teats in the washing machine or boil them several times to soften them.
- “*Haberman*” type teats are recommended for children with very weak suction or with an oro-facial cleft.
- “*Remond*” type teats are recommended for children who are prone to reflux.

The Reflux

Regurgitation is a frequent problem with babies. However, if you observe signs of pain, unexplained crying or sleeping difficulties **your child may be suffering from gastro-oesophageal reflux (GORD)**. It is then important to consult your doctor for the reflux to be treated.

To soothe your baby you can:

- Position your baby such that his back is as vertical as possible during the feeding and digestion process. This will also prevent the risk of food reflux through the nose.
- Put a sloping surface under his mattress at the level of the chest
- Massage his tummy
- Thicken the milk (with special thickeners for children) or choose an anti-regurgitation milk.

Preventing swallowing the wrong way

- Preferably feed your baby whilst sitting down. It is important for his head not to fall backwards.
- It may be advisable to thicken the milk if the baby has a tendency to swallow the wrong way during feeding.

Non-nutritional Sucking

If your baby is being nourished via a naso-gastric tube, it is still important to maintain his sucking and swallowing mechanisms. Very often, even if his sucking is insufficient for him to nourish himself, he will be able to suck a little teat or your finger.

This may appease him and reinforce the muscles of his orofacial sphere.

Little Massages

Use moments of peace and interaction with your baby to stimulate his face gently by:

- Stroking from the ears to the lips and massaging chin and cheeks in a circular motion
- Tapping with the tip of your fingers around his mouth and on his lips.

"I can remember that in the neo natal unit, nurses would insert a little mini teat in his mouth that he couldn't manage to hold in well, but which helped to calm him a lot.

Sarah

From 3 to 18 months

At around 6 months an infant starts to sit, goes from an exclusively milk based diet to a more diversified diet and starts to eat with a spoon. In reality verticalisation of the body (going from lying down to sitting and standing) and food diversification go hand in hand. Be aware though that the presence of teeth does not automatically mean that you have to start spoon feeding.

Feeding with a Spoon

At the beginning your baby will suck on a puree or compote, with his tongue making to and fro movements; the tongue starts to gain better control of the food by swishing it from left to right.

Some children, in particular those with an oro-facial cleft, will start well before six months to suck milk off a spoon.



Posture Advice

- Your child should be sitting comfortably on your knees or in a high chair with a nice straight back.
- Put the spoon on your child's tongue by **introducing it from the side** and turning it over on his tongue.
- Do not spoon off the rest of the puree with the spoon as this can be too forceful for the child.
- **Try different types of spoon** to find the one that suits your child best.

“Meal Times”

As soon as possible take your mealtimes together as a family. **At the table your child will observe you eating and will try and imitate you.** He will also like to imitate his peers or brothers and sisters. **The little rituals of the meal will reassure your child:** preparation of the meal, setting up the table, moments of conviviality, the sight of the food, the mouthing of the puree, hunger being appeased...

Taming Food

Your child is a proper little explorer: his five senses are all awakened when he discovers food!

Messing with it and spreading it on his face give him precious information that will allow him to progress with his feeding.



The Visual Aspect is important to appreciate a meal; when you have time, have fun by making amusing presentations using colourful napkins and cutlery.

Your child may also have difficulties in taking control of his mouth and may not want to touch his food. **First help him to tame his senses in other ways**, by touching different non-food textures (screwed up paper, furry objects, play dough), smelling the scent of a cake in the oven, putting his hands in sand, listening to popcorn popping in a pan, looking at different displays at the vegetable market, playing with a doll's tea set

It is important that your child knows what is on his plate. As much as possible take him shopping with you and **show him the food, let him touch it, name the items for him.**

You can also use picture books from a very early age, fruit and vegetables, the kitchen ... It will contribute to the enriching of his vocabulary. **Don't hesitate to prepare meals in front of him so that he sees the different stages of food preparation.**

Your child puts a lot of effort into eating and tires easily. Favour small helpings in small containers and pause frequently.

Nutrition

■ **If your child is a poor eater then you have to increase the calorific value without increasing the volume of the meal.**

Enrich his meal with fresh cream, melted cheese, butter, oils (olive), tapioca, eggs, béchamel sauce ground meat, honey, powdered milk...

■ **When a child is constipated, he is not hungry!**

To facilitate the transit he must drink water rich with magnesium and eat fibres (whole grains, dry vegetables, red berries...), lubricate his motions by the consumption of fats (oils, butter).

"Transition to spoon feeding was easier than it was to bottle feeding... Our daughter touched the food before we put it in her mouth – she needed to know how it felt."

Olivier

Artificial Feeding

When feeding your child by mouth becomes impossible or insufficient, feeding by a tube (nasogastric, gastrostomic...) needs to be considered. During this period **it is essential to maintain the sucking reflex.**

- Just before or after insertion of the tube, if your child's health allows this, you can give him a few drops of milk or a spoonful of puree. This will induce salivation and awaken the digestive system.
- During the use of the tube, encourage your child to suck your finger or a teat. You can apply gentle pressure on his tongue to stimulate the sucking reflex.

Continue to stimulate his taste and smell organs!

If your child can taste food orally, **the culinary discoveries should take place before the use of the tube.** If your child's hunger has been satisfied by the use of the tube, he will not want to eat anything else, however little there is. Even if your child is being fed by tube **it is important that your little one should participate in the meal time with you**, so that he shares the moment of conviviality, exchange and learning of a culinary nature.

Buco dental hygiene

His little teeth are very fragile and subject to cavities, it is important to brush them as soon as they appear (with toothpaste, a little toothbrush or a finger tooth brush especially for babies).

It is best not to let your child go to sleep with a bottle of milk in his mouth (if need be, only a bottle of water).

The little massages

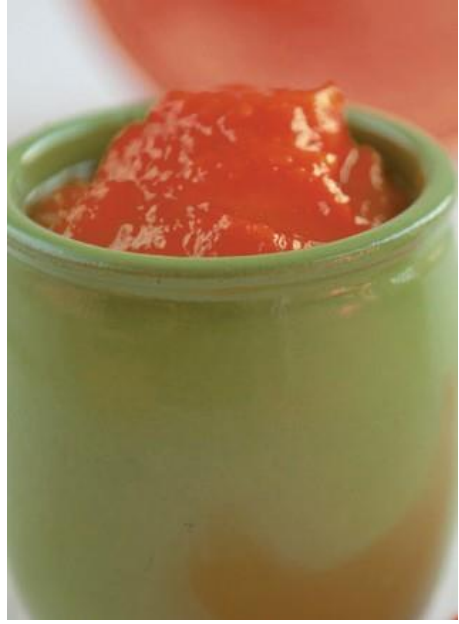
To stimulate his orofacial sphere you can do the following:

- Touch lightly on his cheeks, around the mouth, on the lips...
- Massage under his chin to help him swallow. That will also help your child to swallow his saliva if he dribbles a lot.
- Massage his gums from the inside of the cheeks...

Little tip: to vary the stimulation you can use different tips placed on your index.

Put what you are doing into words, warn your child before touching his face. To be as unobtrusive as possible, start from the outline of his face, or even his arm, and go towards the mouth, by playing tickling games for instance...

Your child must also be allowed to explore his mouth and face himself!



From 18 months to 3 years

Little by little the movements of the lower jaw, tongue and cheeks of the infant become more coordinated allowing him to chew more and more solid food. This evolution parallels the progression of the first steps. Learning how to chew is a long and complex process which last until the age of 4 to 6. It is common for children to encounter some difficulties.



Introducing new foods

Of course the child must learn to taste everything but **he must never be forced to eat**. This could lead to food resistance.

Showing a new food to a child several times will help him to accept it. You can also offer it with another food he likes to ease the transition.

Mealtimes

Even if mealtimes are troublesome, they should not become a source of stress for you or your child. This is above all a moment of pleasure, to share and to imitate. **Singing songs, telling stories, making funny faces, affectionate gestures can all de-dramatise the moment.**

Small quantities

It is important to only give the child **quantities suitable for his appetite and that he can handle, so as not to discourage him.**

You can also offer small portions to your child in small mouth size pieces that he can eat with his fingers.

"Our son used to eat a lot without chewing. It was very stressful for us. But it was so nice to see him enjoying himself. He ate with his hands, spreading the food over himself. He particularly liked doughy things with strong flavours."

Emilie

Learning to blow the nose

A good nose blowing technique allows the child to:

- clean out his airways
- clear the eustachian tubes (little canals connecting the eardrum to the pharynx),
- learn that he can breathe through his nose.

First make sure that your child is aware of his nose. Little ones are often under the impression that it only serves to make the face look nicer!

Little tip: blow with your nose onto a hand mirror, keeping your mouth closed, then show your child the clouds created by the mist. Stand sideways and exaggerate the gesture, so that your child understands that air comes out of your nose.

You can also “do the dragon” by dilating your nostrils! **Slowly you can show him how to blow his nose one nostril after another. It is important!**



Sense of smell

To be able to enjoy the taste of a food, you need to be able to smell it. You know how unenjoyable eating is when you have a cold. Get your child accustomed to eating and recognizing different smells in the kitchen (spices, cheese, chocolate...) and from the everyday environment (soap, flowers...).

Preventing food from going down the wrong way

To stop food from going down the wrong way it is best if the child eats whilst sitting down with a straight back. **Hold his head up if necessary**, so that it does not go backwards whilst swallowing.

If your child is experiencing difficulty in propelling the food down to swallow it **you can lubricate the food** by adding butter, oil or stock...

Adaptive aids

Ergonomists have designed adaptive aids to help with children with motor function difficulties which are available for sale on the internet or in specialized stores, don't hesitate to visit them! You will find drinking cups with soft, hard or scalloped spouts, bent spoons and forks for scraping, sloping plates, aids to chewing... **These aids will encourage your child to experiment and to feed himself.**

Simple facial movements

To chew, speak, smile, cry, make faces, your child needs to develop his orofacial muscles.

The simple facial movements use all the key zones of the face and the mouth. In particular if your child's face is hypotonic (with low muscular tone), these facial movements will be very useful. Sit down with your child in front of a mirror; this will help him to imitate you.

- Make him alternate making a big clown smile and then blowing a kiss, this will improve the muscular tone of the lips!
- Make him alternate blowing out his cheeks with sucking in his cheeks; this will improve the tone of his little cheeks.
- Make him stick out his tongue and try to touch his nose with it; this will strengthen his tongue,
- Make him drink with a straw (if he can handle them, straws in the shape of spirals can be purchased) and make him blow on objects of increasing weight or further and further away. Offer him a harmonica (they have the advantage of making music when both sucking and blowing), this will strengthen the soft palate! During these games ensure that the lower jaw of the child is not sticking forward.
- Make noises (like a fish, horse, car...) whilst playing.

These games can be played with the child in various situations: in the bath, whilst telling a story or reading a rhyme...

You will find more ideas on these repetitive little movements in the booklet "Little repetitive movements for little ones" or, of course with a speech therapist.

About language

Verbal ability develops at the same time as the ability to eat. Both develop by using the same body component, the mouth. Everything you do on a day to day basis to help your child improve his feeding, to explore his mouth, to blow, to smell... will also help him to develop his speech and his language ability! More information can be found on website information on speech.

EVOLUTION
OF
TEXTURES

LIQUIDS

VERY
SMOOTH
PURÉE

MASHED
PURÉE

Choice of textures and how to adapt them

Slowly modify the food texture, step by step, following your child's rhythm. Let him experiment with the food so that he takes in the different consistencies. It is possible that the stage where small pieces or lumps are introduced will be difficult and that your child will refuse them, only accepting finely pureed food.

Soft solids

Introduce soft solids slowly. **This consistency can be less stressful than the solids with lumps or bits and will allow the child to continue the chewing movement.**

- Soft cheeses (like Laughing Cow). Give these at room temperature so that they are softer and easier to chew.
- Flans (like *Flanby*), sponge cake, mousses and soft tofu...

Finger foods

Offer small mouth-size bites that can be picked up with the fingers:

- Mini quiches without pastry (you can make them without crust, recipes can be found on the internet) in which you can mix swished vegetables that your child likes.
- Little salty flans, cod pieces ... to dip into sauces
- Small pieces of fruit and vegetables
- Snack foods such as "Monster Munch" or "Curly" (the strong peanut taste and the crunchiness are often popular). Your child can also dip them in smoked cod's roe or soft cheese like Boursin or creamy blue cheese...
- Stick shaped cakes, such as the Mikado product

Calorie rich meals

If your child is a poor eater, enrich his meals as much as possible, without increasing the quantity to be ingested. Favour small containers (saucers, little individual ramekins, small bowls...).

SOFT
SOLIDS

HARD SOLIDS
CHOPPED UP
FINELY

HARD SOLIDS
WITH LUMPS

- Add to soups: tapioca, fresh cream, powdered milk, gruyere cream...
- Add to cheesy dishes, lasagnas: grated cheese, fresh cream béchamel, butter...
- Add to raw vegetable platters: hard boiled eggs, potatoes, bacon bits, walnut oil, olive oil... Avocado (just like banana) is very rich in calories.
- Incorporate into desserts: a layer of chocolate or fruit, condensed milk, chestnut cream, honey, custard...

Do not hesitate to add other types of calories and include several different types in a single meal.

If need be there are very rich good supplements for children (such as Fortimel for baby).

Food going down the wrong way

If your child is prone to food going down the wrong way or has difficulty chewing, avoid the following foodstuffs:

- **multi-textured foods** (soups with lumps, juicy fruits, milk with cereals)
- **fibrous foods** (leeks, celery...),
Consider cooking them thoroughly and pureeing them, if your child likes them.
- **food in grains** (rice, semolina, peas, muesli...),
Thoroughly cook pasta so that it dissolves in the mouth.
- **crunchy, crumbling food** (biscuits, croissants, crisps...),
Use sliced bread, brioche, cake... instead. Tuc biscuits have an interesting texture as they melt instantly in the mouth
- **foods with thick skins** (sausages, smoked ham that is too elastic),
- **foods that are too dry** (tuna, egg yolk) they are hard to swallow.
Make sure you lubricate dishes by adding oils, butter, mayonnaise...

Give your child chilled drinks, this is more stimulating and encourages better swallowing. Fizzy drinks are also recommended. If swallowing the wrong way is too frequent an occurrence, liquids (water, fruit juice) can be thickened with specialised thickening agents sold in chemists.. You can also thicken water by adding a bit of compote. The gelatinous water will also allow your child to be properly hydrated.

If in any doubt, do not hesitate to contact a dietician or speech therapist.

Rhyming Games

I GO AROUND MY HOUSE

- I go around my house (run your finger around the child's face)
I go down the stairs (let your finger run down the child's nose)
I ring the doorbell (press on the tip of his nose)
Hello Daddy (press on one cheek)
Hello Mummy (press on the other cheek)
I wipe my feet on the doormat (rub just below the nose)
I come into the house (put your finger in the child's mouth)
And I lock the door (twist your finger on the child's lip)



GOOD NIGHT!

Useful links

- **www.especialneeds.com**: For purchasing adaptive aids online
- **www.orpha.net** : Portal for rare diseases and orphan drugs
- **info-langage.org** : Website specializing in the prevention of language difficulties
- **sparadrap.org** : Association promoting health for children worldwide
- **www.williams-syndrome.org.uk**: UK Williams Syndrome Foundation website
- **asso.orpha.net/AFSCDL** : French Association of the Cornelia de Lange syndrome

And many others!

**This booklet has been
prepared in memory of
speech therapy by Jasmine
Don and Madeleine Gaquiere.**

We express our gratitude
to: Catherine Thibault (speech therapist and
psychologist), Laure Soulez Larivière (speech
therapist and dietician),
Carole Hervé (breast feeding
counselor) for their precious advice.

Translated into English by Anna Bethune

You can find this leaflet in PDF
form on [www.williams-
syndrome.org.uk](http://www.williams-syndrome.org.uk) or in French on
oralite-alimentaire.blogspot.fr/
contact : don.gaquiere@gmail.com

Graphics : Romain Ricordel