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Understanding  
**NUTRITION  
CHOICES**

during your child's illness

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INFORMATION AND DECISION AID

The quotes you see in this booklet are real quotes from parents and carers of children who are sick, or the children themselves. None of the quotes were spoken by the people in the photos in this booklet. We would like to thank all the parents, carers and children for sharing their stories with us and for giving us permission to use their quotes and photos in this booklet.

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# About this Decision Aid

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This decision aid is for you, as a parent or carer, if your child is currently in hospital.

In this decision aid you will learn about how important nutrition is for your child while they are in hospital. There are a number of ways we can help your child to get the nutrients they need. This is called '**nutrition support**'. This booklet will help you to think through these options, and come to a decision about which method of nutrition support you might like for your child.

This decision aid is just a guide. Please discuss the options presented here with your child's **dietitian** and doctor.

Throughout this booklet some words are **bolded**. If you are not sure what a bolded word means, you can find the meaning in a list at the end of the booklet.



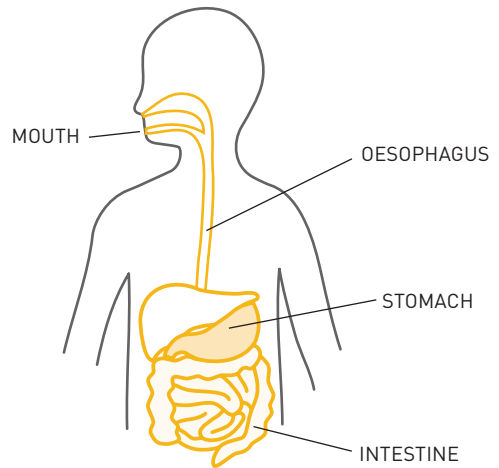
# The importance of good nutrition during illness

## How illness leads to poor nutrition

As a growing child, your child needs a balanced intake of **proteins, carbohydrates, fats, vitamins** and **minerals**. Usually your child gets these nutrients from their food. When your child eats, the food travels down into the **stomach** and **intestine**.

Here, it gets broken down again and again into smaller and smaller pieces. This is called '**digestion**'. When the pieces are small enough, they travel across into the bloodstream – this is called '**absorption**'. The pieces that have been absorbed are the nutrients that your body can use.

If your child does not get enough nutrients in their diet, they might lose weight or become underweight. We would say they have poor nutrition. This would mean that either your child is not eating enough or their body is not absorbing enough nutrients from their food.



When your child is sick, they can end up with less nutrition than they require through three main ways:



### 1. They eat fewer nutrients than usual

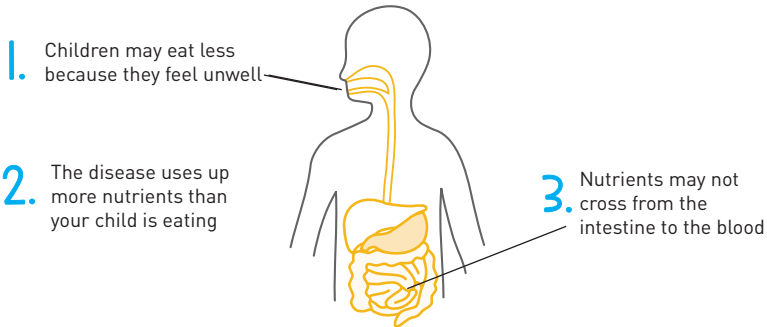
Your child's appetite may decrease. Often when children are unwell, they do not feel like eating. This might be because of symptoms associated with their illness, such as nausea, stomach cramps or spasms. When children feel sick it is understandable that they may want to eat less. This means that they might not eat enough or eat the right foods. They end up eating fewer nutrients than they need.

### 2. They use up more nutrients than usual

Some illnesses, such as chronic kidney disease and the treatment it requires, mean your child needs lots of energy to keep growing quickly. The disease may use up the nutrients your child's body would normally use, not leaving enough for growth and normal functioning.

### 3. The nutrients they eat may not be absorbed and used as well as usual

Some illnesses affect the lining of the stomach and intestine. This means that children may not be getting all the nutrients they could from the food they do eat. Although the food travels down into the stomach and intestine, and gets broken down into smaller and smaller pieces, those pieces are not able to cross into the bloodstream because of the damage and are lost in the stool.



## The effects of poor nutrition

During illness, losing weight can stop the body from doing its job. There are three main sources of energy: **fats**, **carbohydrates** and **proteins**. When the body is not getting enough energy, it starts to use its fat and carbohydrate reserves for energy, and starts breaking down muscle for protein.

This is why having poor nutrition has such serious effects, especially when your child may need extra energy to get through their illness. Better nourished children recover better from their illness.

There can be important short term effects if your child has poor nutrition.

## What happens when your child has poor nutrition?



Not having enough energy means children first use up their energy stores such as fat. The body then starts to break down the protein in their muscles. This leads to weight loss, from losing fat and muscle. This can make your child feel more tired and weak.



Not getting enough nutrients means that a child's **immune system** is also affected. The immune system heals the body and fights off infection. The body is able to heal itself less quickly if the immune system is not working well. The cells of the immune system also become weaker and less effective. This means that children are more likely to get an infection.

There can also be serious long-term effects if your child has poor nutrition.



As children are growing and developing, there is a greater energy demand on the body. If they do not get the energy and nutrients they need, this can interfere with their growth. This may mean that children grow up to be shorter and smaller than they would have otherwise. Their bones might also become weaker.



Throughout their childhood, children are also developing important skills. Their brains are developing – they are learning how to think and how to process all of the information coming in from the world around them. They are learning how to move – how to pick up things, how to play, how to interact with the world around them. Losing weight can also interfere with this brain and movement development.

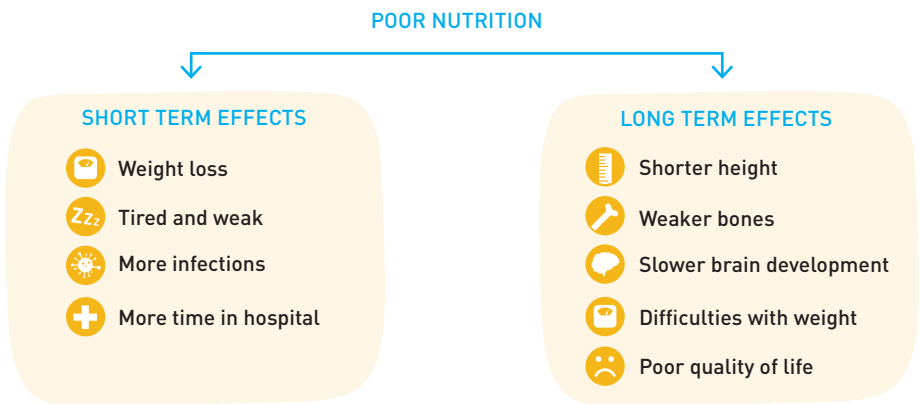


Studies show that children with poor nutrition can develop bad habits towards food and eating in the future.



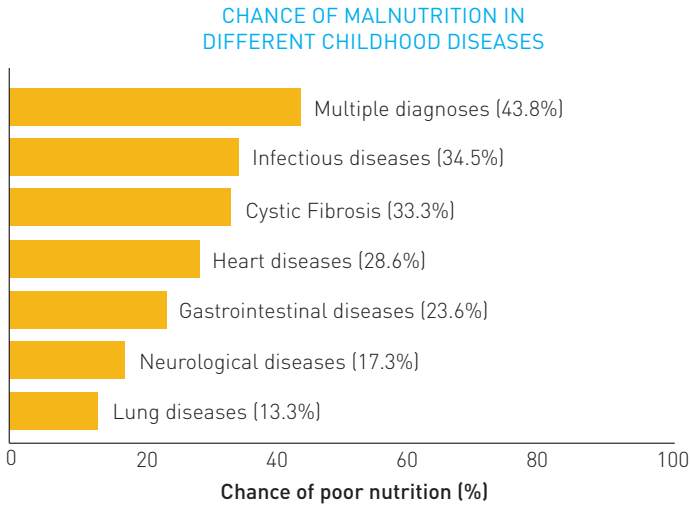
Having poor nutrition can lead to poorer quality of life long-term as well.

As a result, it is important to make sure your child is getting the nutrition they need during their hospital stay. We need to keep an eye out for the signs that they might not be.



## Different illnesses, different effects

Different illnesses have a different chance of causing weight loss. This is because each illness affects a child differently. Some diseases are more likely to cause your child to lose weight than others. As you can see in the graph below, cystic fibrosis or heart disease have more of a chance of causing poor nutrition than children with a neurological disease.



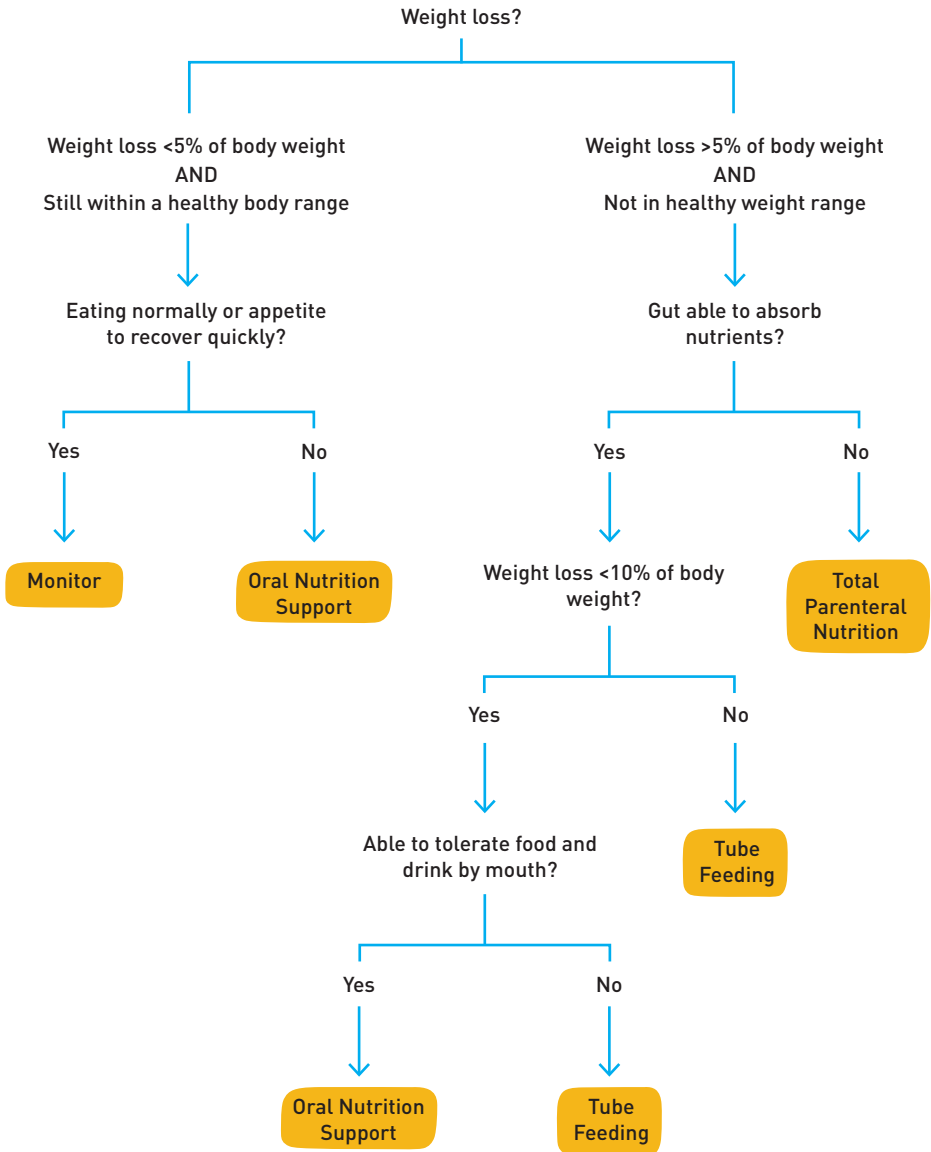
## Thinking about nutrition options

If your child is losing weight or has lost their appetite, you might worry that they are not getting all the nutrients they need. If you or someone involved in your child's care is worried about this, you can talk to a dietitian or a doctor about what you can do. There are four main types of nutrition support to help your child get more energy and nutrition:

- **Oral Nutrition Support:** Encouraging your child to eat foods or pre-made supplement drinks that have lots of nutrients;
- **(Enteral) Tube Feeding:** Putting in a feeding tube through the nose to the **stomach**. Nutrients are given through this tube. This overcomes the loss of appetite. This is one kind of enteral nutrition;
- **(Enteral) Gastrostomy Feeding:** Putting in a tube to the stomach. Nutrients are then given through this tube. This is another kind of enteral nutrition; or
- **Total Parenteral Nutrition:** Giving nutrition directly into the blood.



The figure below gives an example of the way a dietitian would think and what issues they would consider in recommending a particular type of nutrition therapy.



# Oral Nutrition Support

## What oral nutrition support involves

**Oral nutrition support (ONS)** refers to improving your child's nutrition by using high energy foods and drinks. This can be through using normal foods that they already like that are rich in nutrients and energy. If your child is having trouble eating those foods, the next step would be to introduce high energy drinks. These could be drinks that you make yourself, or pre-made commercial drinks.

## The benefits of oral nutrition support

Maintaining your child's nutrition through this method has a lot of benefits for your child.

- Oral nutrition support can help make things feel more normal while your child is sick.
- Oral nutrition support helps to keep the **digestive system** working. This is because food is travelling through the normal pathway for food. This can lower your child's chance of getting infections.
- This method of nutrition support is not **invasive**, as it does not involve any medical procedures.
- Oral nutrition support does not affect your child's appearance.
- Your child does not need to stay in hospital to get oral nutrition support – you can give the extra food or special drinks at home.

## Why you might not choose oral nutrition support

- Oral nutrition support is sometimes just not enough. If your child has an illness that is stopping their food from being absorbed, the doctor might feel oral nutrition support will not help reach your child's nutritional needs. As well, when your child is sick, they may not want to eat at all. On top of that, they might not like the taste and feel of the high energy drinks.
- If your child really does not want to eat, but you and their medical team want them to eat, this can create tension between you and your child.

**“We fought every time... but you are so desperate to have them eating, that you are fighting over food.”**

Mother of 10-year-old female

This may also lead to long-term poor food behaviours. Getting your child to eat is important. However, because your child is growing and developing, the behaviours they learn now can stay with them for life. There are a lot of things which can lead to long term difficulties in children's eating. These include:

- putting pressure on children to eat
- giving children foods that have lots of energy but are not very good for them (like junk food or fast food)
- using food as a reward or 'bribe'
- using other things as rewards for eating, such as toys and time on electronics.
- Although you might think, 'I'll just do this while they are sick, but once they are better we'll go back to eating healthily,' these new behaviours can stick around. These practices teach children to think about food in ways that are less healthy and can affect their eating in the long term.



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## ORAL NUTRITION SUPPORT

### PROS

- More comfortable and normal
- Lower chance of infections and organ damage
- Not invasive
- Do not need to stay in hospital
- No effect on appearance

### CONS

- Can lead to long-term less healthy food behaviours
- Possible tension between parents and children
- Children may still get poor nutrition
- Long-term survivors can have difficulty staying at a healthy weight
- Can be difficult to go back to normal ways of encouraging children to eat healthily



# Enteral Nutrition

## What enteral nutrition involves

**Enteral nutrition** involves giving pre-made nutrition-rich liquid straight into the **stomach**. Enteral nutrition is used when children have poor nutrition, and **oral nutrition support** is not enough.

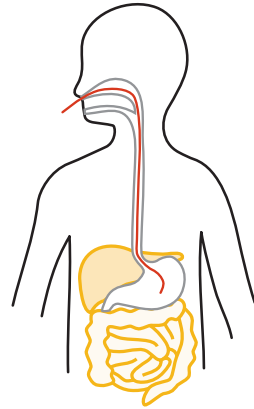
Your child may not require enteral nutrition. The dietitian and doctor will think carefully before considering it as an option.

There are two main ways a feeding tube can be used. The first way involves putting the tube through the nose, down the **oesophagus** and into the stomach. This is called a **nasogastric or NG tube**, and you might often hear it called 'tube feeding'. This method can be done in the hospital ward, by a nurse, **dietitian** or doctor. There is a little discomfort involved.

The second way involves putting the tube through the skin on their abdomen (tummy area), straight into the stomach. This is called a **gastrostomy or G tube**. This is done as a surgical procedure.

NG tubes are used for children who will need the tube for a shorter period of time. This is because they are easy and convenient to use. A gastrostomy is only used if your child is likely to need nutrition for a very long time and they cannot tolerate the NG tubes.

## THE PATH OF AN NG TUBE



## The benefits of tube feeding (NG tubes)

There are a number of benefits of **tube feeding**.

- When children are sick and have lost their appetite, tube feeding helps ensure good nutrition. This is one less thing to worry about. Tube feeding can be done without the child being aware of it. It can even be given during sleep.
- One study looked at ways to treat poor nutrition in children with cystic fibrosis. It found that tube feeding helps children recover better lung function and have a better response to medications whereas **oral nutrition support** was not as helpful.
- Tube feeding takes away the pressure to eat. This means that children are less likely to develop the poor food behaviours associated with feeling pressured to eat.

- Like oral nutrition support, tube feeding is also good for the **digestive system**. Enteral nutrition means that food and nutrients are entering the body through the normal pathway for food. This helps prevent problems with other organs that help to digest food, like the **liver** and **gallbladder**, and also helps prevent **systemic (bloodstream) infections**.
- With NG tubes, the tube can be put in at the bedside, by a nurse, dietitian or doctor.
- Children do not need to stay in hospital to have tube feeding. The nurses can show you how to give the feeds and look after the tube at home.

**“When I found out about it I felt a huge amount of relief that I wouldn’t have to struggle with trying to eat.”**

17-year-old male

### **Why you might not choose tube feeding**

There are some difficulties associated with tube feeding.

- A common concern of parents and children considering tube feeding is appearance. With NG tubes, the end of the tube that comes out of the nose is visible. This can make you or your child feel self-conscious.
- The NG tube itself can be uncomfortable to have in the throat. This can cause sleep problems. Most children who use a feeding tube say that the uncomfortable feeling with the tube goes away after 1-2 days.
- Children can vomit the tube up. This is uncomfortable and means a new tube has to be put in.

**“There was always that part of me that didn’t like the NG tube because I felt like it was causing the patient so much discomfort.”**

Mother of 4-year-old female

“[We] chose tube feedings because it helped keep the digestive system active, making it easier to adjust back to food.”

Parent of 8-year-old female



## TUBE FEEDING

### PROS

- Prevents poor nutrition
- Removes pressure to eat
- Lower chance of infections and organ damage
- Not very invasive
- Do not need to stay in hospital

### CONS

- Appearance of having a tube through the nose
- Uncomfortable
- The tube can be vomited up (emesis)

## The benefits of a gastrostomy (G tube)

The benefits of a gastrostomy are very similar to the benefits of tube feeding.

- A gastrostomy also helps ensure good nutrition. This is one less thing to worry about while your child is sick.
- A gastrostomy again takes away the pressure on children to eat.
- A gastrostomy is also good for the **digestive system** because nutrients are entering the body through the normal pathway for food. This helps support the digestive system's normal functioning.
- Children do not need to stay in hospital to have a gastrostomy. The nurses will show you how to give the feeds and look after the tube if your child requires feeding at home.

## Why you might not choose a gastrostomy

There are extra issues associated with G tubes.

- Acid from the stomach can leak out, and irritate the skin around the tube.
- Children can also get small infections of the skin around the site of the tube. These infections are uncomfortable and can be painful, but can be treated with antibiotics.
- G tubes also require surgery to be put in. As with all surgical procedures, there is a chance of bleeding, pain and reaction to the **anaesthetic** drugs.
- With long term use of a feeding tube, children can develop '**tube dependence**'. Tube dependence refers to when a child no longer needs a feeding tube, but still wants to keep using it. They are used to having a feeding tube in, and stop wanting to eat orally. This can happen when the tube has been in for a long time.

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## GASTROSTOMY

### PROS

- Prevents poor nutrition
- Removes pressure to eat
- Lower chance of infections and organ damage
- Do not need to stay in hospital

### CONS

- Chance of skin irritation or infections
- Surgery
- Chance of tube dependence

# Total Parenteral Nutrition (TPN)

## What TPN involves

TPN involves putting nutrients straight into the blood, through a vein. This can either be through a major vein in the arm or leg (a peripheral vein) or a vein next to the heart (a central vein).

Your child may not require TPN. The dietician and doctor will think carefully before considering it as an option.

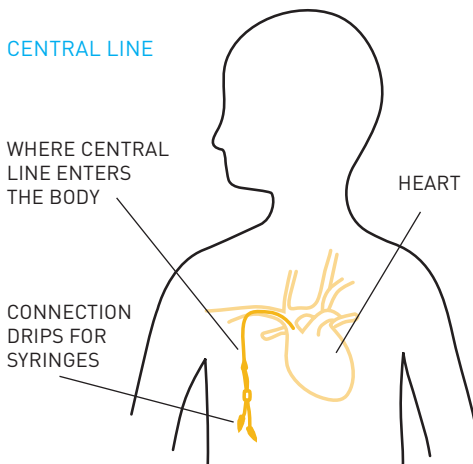
Some drugs are also given straight into the blood - this is called intravenous therapy.

If your child is receiving intravenous therapy, they may already have a port in place that goes into a vein next to the heart. This is called a **central line**. This can be used to give TPN. Most children in hospital do not have a central line in place.

TPN can also be given through a PICC line, or a peripherally inserted central catheter. This is a tube that is usually inserted into a vein in the arm. The tube goes up into a larger vein next to the heart. Most children in hospital do not have a PICC line in place.

With TPN, the nutrition is connected to the needle and infused into the blood.

Inserting a central line or a PICC line is a surgical procedure. Your child will need a general anaesthetic. For this reason, TPN is sometimes not a suitable option for your child.



## The benefits of TPN

- TPN reduces the chance of weight loss and removes the pressure on your child to eat.
- If your child already has a **central line**, such as for giving medications, using TPN is convenient. Your child will not have to undergo any extra procedures to put in a needle.
- TPN avoids the discomfort of **tube feeding**.
- TPN is less visible than a **nasogastric (NG)** (tube through the nose). This reduces the chance of your child being self-conscious about their appearance.
- Your child's **digestive system** might not be able absorb nutrients, for example, if they have bad diarrhoea and the intestine is damaged. When this happens, the nutrients in the intestine cannot cross over into the blood to be used by the body. In this case, the best option is TPN.

“When our child was on [TPN] it was very simple for our family, which made life a little more ‘normal’.”

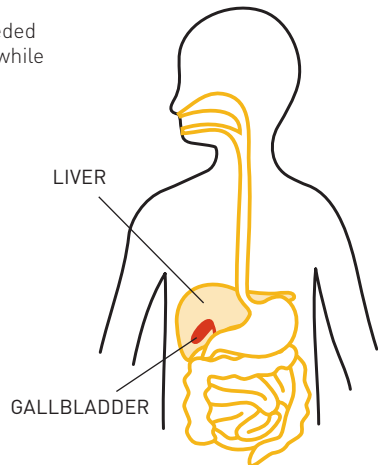
Parent of 13-year-old female

## Why you might not choose TPN

Although **TPN** is convenient and more comfortable than tube feeding, there are some important issues to consider when using TPN.

If your child does not already have a central line in place, TPN may not be the best option for nutrition. This is because inserting a central line is a high-risk procedure. Central lines and PICC lines are inserted under general anaesthetic.

- TPN is not helpful if nutrition support is only needed for a few days. This is because the body takes a while to convert the TPN feed into useful nutrients.
- While children are on TPN, they must stay in hospital. The nurses need to give the nutrition and look after the **central line**.
- The **liver** and **gallbladder** release substances that help breakdown food in the intestine. When children are on TPN, the liver and gallbladder are not being used. This can cause them to become damaged. If this happens, your child should recover once they stop using TPN. However, if TPN is used for a very long time, the damage can be permanent. With careful monitoring of the liver, this is unlikely.



- When children don't eat using their digestive system, the intestine can get damaged. This can lead to bacteria in the intestine getting into the blood and causing serious **systemic (bloodstream) infections**. With careful monitoring, this is also unlikely.
- Last but not least, when children have a central line, the port into the vein is a pathway for bacteria to go directly into the bloodstream and cause a **systemic infection**. If your child already has a central line, using TPN will not increase their chance of developing a serious infection. Good medical care of the central line can make the chance of developing an infection very low.



## TOTAL PARENTERAL NUTRITION (TPN)

### PROS

- Prevents poor nutrition
- Takes off pressure to eat
- Convenient if already have a central line
- More comfortable than tube feeding
- Not visible

### CONS

- Must stay in hospital
- Chance of liver damage and gallbladder damage
- Chance of systemic infections
- Not helpful if nutrition support is only needed for a few days
- Chance of intestine damage



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# Making Your Decision

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## Step 1: Clarify the decision

Try to put the decision you are making into your own words. For example, 'I'm trying to think through the options the dietitian suggested for improving my child's nutrition.'

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What are your reasons for making this decision?

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## Step 2: Compare the options

### a. What am I comparing?

In the following pages are some tables that relate to each nutrition support option described in this decision aid. First consider whether your child's dietitian and doctor have said that method of nutrition support is an option for your child, and place a tick or cross in the box. If you place a cross in the box, skip that option.

### b. What I know

The following pages list most of the pros and cons associated with each nutrition therapy option. If there are any other pros and cons you can think of, just add them to the table.

### c. What is important to me?

Show how important each pro and con is to you by writing zero to five stars (★★★★★) in the columns labelled 'personal importance'. If a pro or con is not at all important to you, then give it zero stars.

**d. How sure I feel**

Using the scale at the bottom of each table, tick the box that reflects how you feel about this nutrition support option. The option with the pros that are most important to you is probably the right option for you. Avoid the option with the cons that worry you the most.

For a tough decision like this, people rarely feel completely sure. With careful decision-making, many people feel better about and more comfortable with their choices. Most people are also glad they made a written record of what mattered most to them when making the decision.

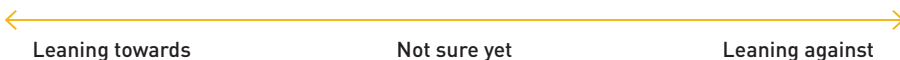
**Thinking about oral nutrition support**

**Has my child’s doctor or dietitian said this is a possibility for my child?**

If not, skip this option. If so, show how important each pro and con is to you by writing zero to five stars (★★★★★) in the columns labeled ‘personal importance’.

| <b>PROS</b>   | <b>PERSONAL IMPORTANCE</b><br>★★★★★ | <b>CONS</b>   | <b>PERSONAL IMPORTANCE</b><br>★★★★★ |
|---|-------------------------------------|---|-------------------------------------|
| More comfortable and normal   |                                     | Children may still get poor nutrition   |                                     |
| Keeps <b>digestive system</b> working, lowering the chance of infections and organ damage |                                     | Possible tension between parents and children                                       |                                     |
| Not <b>invasive</b>   |                                     | Can lead to long-term less healthy food behaviours                                  |                                     |
| No effect on appearance   |                                     | Long-term survivors may have difficulty staying at a healthy weight                 |                                     |
| Do not need to stay in hospital   |                                     | Can be difficult to go back to normal ways of encouraging children to eat healthily |                                     |
|   |                                     |   |                                     |
|   |                                     |   |                                     |
| <b>TOTAL:</b>   |                                     | <b>TOTAL:</b>   |                                     |

At this point in time, are you leaning towards oral nutrition support or not?







## Thinking about TPN

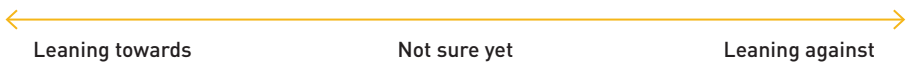
Has my child's doctor or dietitian said this is a possibility for my child?

If not, skip this option.

If so, show how important each pro and con is to you by writing zero to five stars (★★★★★) in the columns labeled 'personal importance'.

| PROS  | PERSONAL IMPORTANCE<br>★★★★★ | CONS   | PERSONAL IMPORTANCE<br>★★★★★ |
|---|------------------------------|--|------------------------------|
| Prevents poor nutrition                                       |                              | Must stay in hospital  |                              |
| Takes off pressure to eat                                     |                              | Chance of <b>liver</b> and <b>gallbladder</b> damage           |                              |
| Convenient if children already have a central venous catheter |                              | Chance of serious <b>systemic (bloodstream) infections</b>     |                              |
| More comfortable than tube feeding                            |                              | Not helpful if nutrition support is only needed for a few days |                              |
| Not visible   |                              | Chance of <b>intestine</b> damage                              |                              |
|   |                              |  |                              |
|   |                              |  |                              |
|   |                              |  |                              |
| TOTAL:  |                              | TOTAL:   |                              |

At this point in time, are you leaning towards TPN or not?





# What to do now

## What to do if you'd like a referral to a dietitian

If you are worried about your child's nutrition, you may want to discuss your worries with a **dietitian**. If you talk to your child's doctor, they can put you in contact with the dietitian.



## Some words used in this booklet

**Absorption:** the process by which nutrients cross from the intestine into the blood. Once in the blood, they can be used by the rest of the body.

**Carbohydrates:** one source of energy for the body. Carbohydrates are found in foods like bread and rice.

**Central line:** a port that goes into a vein next to the heart. These can be used to give medications, fluid or TPN (total parenteral nutrition).

**Chemotherapy:** one type of treatment for cancer. This involves giving drugs that kill off cancer cells.

**Dietitian:** someone whose job involves making sure people have good nutrition.

**Digestion:** the process by which the food you eat gets broken down into nutrients that you can use.

**Digestive system:** the parts of the body that turn food you eat into nutrients that your body can use.

**Fats:** one source of energy for the body. Fats are found in foods like oil and nuts.

**Gallbladder:** an organ in the body that helps you break down and absorb food.

**Gastrostomy (G tube):** a tube which goes through the skin on the abdomen (tummy area) into the stomach. This is used to give food straight into the stomach.



**General anaesthetic:** drugs which are given to make someone unconscious. This means they can have surgery without feeling anything.

**Intestine:** the part of the digestive system that comes after the stomach. The intestine helps break down and absorb nutrients.

**Immune system:** the part of your body that helps fight infection and heal your body.

**Intravenous chemotherapy:** chemotherapy that is given through a vein into the blood.

**Invasive:** when medical objects must be inserted into the body.

**Liver:** an organ in the body that helps you break down and absorb food.

**Minerals:** nutrients that the body needs to function normally, such as calcium, iron and zinc.

**Nasogastric (NG) tube:** a tube through which food is given. It runs from the nose to the stomach.

**Nutrients:** substances that your body needs to function normally.

**Oesophagus:** a tube in the body that connects your mouth to your stomach.

**Oral nutrition support:** one way of giving more nutrition to someone. This involves giving them more foods, or pre-made commercial drinks with lots of nutrients.

**Protein:** one source of energy for the body. This is what muscles are made of. Proteins are found in foods like meats and legumes.

**Sedation:** when someone is given drugs to make them lose feeling, but not become completely unconscious.

**Stomach:** one part of the digestive system. It produces acid to break down food.

**Systemic infection:** a serious infection in which the bacteria get into the bloodstream and travel throughout the body.

**Total parenteral nutrition:** when nutrients are given directly into the bloodstream.

**Tube feeding:** giving food through a tube which goes through the nose into the digestive system.

**Vitamins:** nutrients that the body needs to function normally, like vitamin A, vitamin C and vitamin D.

## Scientific studies used to make this booklet

### Scientific studies mentioned in the booklet

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