

# Trichothiodystrophy (TTD)

Getting the right nutrition and  
fluids

## Growth in Trichothiodystrophy (TTD)

Children and young people with TTD have a different growth pattern due to the nature of their underlying condition.

Although their growth pattern is not as severely affected as in children with Cockayne syndrome, there are some similarities. The differences in growth pattern are well recognised.

They do not need the same number of calories as other children of the same age. The amount of protein they need may also be different.

Each child is treated individually, so the amount of calories and protein they need is different. Currently, we do not have specialist growth charts, like the charts we have for Cockayne syndrome. However, we are working with our clinical colleagues across the world to develop them. We currently use standard growth charts so that the dietetic team can assess your child and formulate a feeding plan based on their individual needs.

It is important to look at your child and their weight rather than their age when assessing the calories they need. The size of your child's stomach is about the size of their fist so this may help when thinking about how much they can manage for a meal or drink.

Giving more calories does not necessarily mean an increase in height or weight. Instead it can cause your

child to be sick (vomit) due to the small stomach volume.

## Calories and nutrition

Research shows that giving the right number of calories is essential for the health and well-being of children and young people with TTD. Giving too many or too few can be harmful. However, it is not just about calories, giving the right amount of other nutrients is equally important.

## Type and texture

Some children with TTD may have difficulty with eating when they are younger. This may become easier as they get older, although they may continue to have a small appetite.

The type and texture of food that children and young people are able to eat can also vary. They may be sensitive to certain foods, which can irritate the stomach and digestive system, causing a loose stool (poo) or constipation. Speak to your dietitian for advice.

Sometimes dry foods can break off and scatter in the mouth causing coughing or difficulty chewing. Let your clinical team know if your child is coughing when eating. You should also let your clinical team know if there is any change in the type of food or fluid your child is able to take. We can advise on how to continue to give food and drink by mouth safely.

We may recommend having soft, moist food or making sure food is cut up into small pieces. These suggestions may make it easier for your child to eat.

## Feeding support

Some children and young people with TTD will need support with feeding. Sometimes it is not safe for them to eat food or take fluids by mouth. This is often because their swallow may not be strong enough. There is a risk that food or fluid may go into their lungs.

This may mean that enteral feeding (using a feeding tube) is necessary to give your child the calories and nutrition they need.

### Feeding tubes

In this information we use the term 'feed' when we are referring to the medicinal product which patients receive through their tube. By using this term, we are consistent with widely used clinical terminology. This avoids potential confusion between the terms 'food' (usually taken by mouth) and 'feed' (taken via a tube), which could put patients at risk of harm if interchanged. If you have any questions, please speak to one of our team.

### Nasogastric (NG) tube

This is a tube that passes from the nose into the stomach. We may recommend this as a short-term solution for safe feeding. It should not be used to give feeds or fluid overnight, or be used unsupervised.

## **Gastrostomy tube**

This is a tube that is placed directly into the stomach through the tummy (abdomen). We may recommend this as a long-term solution. A gastrostomy tube needs to be inserted under general anaesthetic, so your child is asleep when this is done.

It is important that the amount of specialist feed and fluid given is carefully calculated to prevent giving too much. This could cause your child to vomit. The calculations take into account any food or fluid taken by mouth.

Feeds may sometimes need to be given slowly by a pump, or a little quicker by a bolus. This is done by using a syringe and allowing gravity to dictate the speed and not by using the plunger. Wherever possible feeding overnight is avoided. This can disrupt the natural sleep cycle, interfere with how the body uses energy, and may affect repair that happens during this time. However, for some children and young people an overnight feed may be needed to make sure enough fluid and nutrition can be given.

**It is important to remember that your child's weight is key to getting the feed and fluid intake right, not their age.** The amount your child can tolerate may be different to that of another child with TTD, so each regimen needs to be personalised.

Start with a small volume and gradually increase to make sure your child can tolerate it. We recommend setting a baseline of about 10% to 20% higher than your child tolerated before the tube was inserted. This can be

slowly increased until your child is receiving their optimum amount.

If healthcare professionals are not familiar with TTD they may feel that a significant increase in fluid is needed. This may not be appropriate for your child. If advice is needed, please contact the specialist team.

### **Poor tolerance of enteral feeds**

Some children may not be able to tolerate the specialist feed or regimen that is initially prescribed. If this happens there are other regimens that can be trialled:

- A feed which has a different composition, for example the protein and fat is already broken down.
- If your child is given their feed as a bolus, using a pump that drips the feed in slowly might be beneficial.
- If the feed is still not tolerated, a tube that goes beyond the stomach into the small intestine (a jejunostomy), may be needed.

### **Additives**

It is important to remember that it is not just about getting the amount of calories right. A lower calorie intake may mean other nutrients such as protein, minerals and vitamins are not present in the amounts needed to maintain health.

We might recommend a multivitamin and mineral supplement, or other supplements may be advised to make sure your child gets the right nutrition.

## Eating when unwell

Children and young people with TTD can get ill more often than others. Sometimes this may cause them to have problems with their digestion.

Food may need to be presented in a different way, such as pureed to make it easier to eat. Or, if the stool is loose, it may be helpful to reduce the amount of fibre in their diet. It may take some time for their appetite to return to normal and their stool to improve after being unwell. Contact your dietitian or clinical team for help if you are worried.

When children and young people with TTD are unwell, they may not be able to tolerate the same amount of fluid as when they are well. It is important to contact your clinical team for advice as intravenous fluids (IV fluids) may be needed to prevent them becoming dehydrated.

The Acute Care Plan document, which is part of your TTD passport, will inform clinical teams about the importance of giving the right amount of IV fluids, and not giving too much.

This leaflet was created by the multi-disciplinary team (MDT), in partnership with parents and Amy and Friends.

## Contact us

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Rare Disease Centre,  
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SE1 7EH  
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For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

## Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm **email** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

## NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web** [www.nhs.uk](http://www.nhs.uk)



Patient Information Forum

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