

Growth, digestion & nutrition

Around 60% of people with Dravet Syndrome show some growth and nutrition issues. These include:

- 'Failure to thrive', which means they are small, underweight and grow slowly
- Osteopenia, which means poor bone density
- Scoliosis, a curvature of the spine
- Problems with swallowing, eating, appetite, or absorbing nutrients

Eating, drinking and swallowing

Difficulties with eating, drinking and swallowing are common in children and adults with Dravet Syndrome. They vary from person to person and can be caused by a number of things, including side effects from medication, seizure activity and autism spectrum disorder. If you're concerned about your child's/adult's diet or eating patterns, one of the first steps is to weigh them. If their

weight is normal for them, there's less need for concern about eating or diet. However, if their weight is too low or too high, it's a good idea to speak to your medical team about investigating possible reasons for this.

A food diary could shed some light as to why your child/adult is over or under eating. Regularly recording what they eat will give you useful information about eating habits, patterns and potential triggers for their lack of appetite or their inclination to over-indulge at certain times. It's important to identify, if possible, from the food diary, whether it's the volume or type of food being eaten which is causing their dietary issue. There are several factors that could be contributing to this, including sensory as well as physical responses to food.

If your child/adult is having problems with eating too much or not enough, we encourage you to get a referral to a dietician. They will be able to advise you on techniques to ensure your child/adult is getting the nutrients they need. If they are having problems with swallowing, asking for a referral to a speech and language therapist (SALT) is a good first step. SALTs can advise on swallowing and feeding issues as well as language. Your neurologist or GP should be able to make these referrals.



Tube feeding (gastrostomy)

Sometimes problems with eating, feeding, swallowing or weight loss can become severe. In these cases, a gastrostomy may be an option. A gastrostomy is a surgical procedure for inserting a feeding tube through the abdomen wall and into the stomach.

This can sound like a frightening and drastic measure. In our experience, for the majority of those who do undergo the procedure, it brings many benefits and can help reduce some of the anxieties caused by concerns with eating and nutrition.

There are two main reasons for the gastrostomy. Firstly, severe eating problems may cause difficulties in swallowing, resulting in food going into the lungs in small amounts (this is called 'aspiration'), which can lead to repeated chest infections. In these cases, your child/adult will need to be assessed by a SALT. Secondly, the process of feeding can be

so challenging that the child/adult can't get enough nutrition, even when high calorie supplements are given. Often, gastrostomy is needed due to a combination of these two reasons.

Having a gastrostomy doesn't necessarily mean that eating stops (especially if your child/adult can swallow safely) but it does make it possible for your child/adult to receive the nutrients they need. Tube feeding provides nutrients by delivering liquid nutrition directly into the stomach or small intestine. Medicines can also be given using the feeding device.

There are different types of gastrostomies: the two most common types are 'percutaneous endoscopic gastrostomy' devices (known as PEGs) and low-profile 'buttons'.

A PEG (such as a Corflo PEG or Freka PEG) is usually the first choice of device, as it allows the stomach wall and abdominal wall to join together, while forming a channel (or 'tract') for the gastrostomy. The PEG is placed into the stomach using an endoscope, which is a narrow tube and camera. This operation is usually done under general anaesthetic.



Once the PEG is established, and the gastrostomy tract has healed, you may wish to change the PEG tube or fit a button device (such as a Mini Button, MIC-KEY or Medicina). However, this is not necessary if your child/adult is getting on well with the PEG. The button is a smaller device, which doesn't stick out as much from the stomach. It has a detachable extension set, which is used to give food or medications. An additional procedure will be required if you change to a button device. It's best to talk through options with your medical team.

Whether or not to have a gastrostomy can be a really difficult decision to make. It's important to know that, for some, it can be incredibly beneficial and positively impact all aspects of life.

A Dravet Syndrome UK survey found that 88% of people caring for someone with Dravet Syndrome had high levels of concern before the gastrostomy procedure. Over half (54%) said there wasn't enough relevant information to support them. Afterwards their opinions were overwhelmingly positive, with 88% of carers saying they were happy that their child had had the procedure.

“I regret that the possibility of a gastrostomy was not brought up sooner. There was much anxiety around feeding for both us parents. Anxiety and stress also stemmed from medications so overall family life has been improved vastly from the gastrostomy. At first, I felt like a failure because I couldn't feed my son, but I'm very happy we have this option now.”

Mum to a 14-year-old with Dravet Syndrome

Digestion and toileting

Children and adults with Dravet Syndrome may experience difficulties with digestion and urination. Research suggests that around half may have difficulties with constipation and just over a third experience incontinence.

It's not unusual for children with Dravet Syndrome to toilet train later than average. Depending on the level of disability, some may never be fully toilet trained and may remain incontinent throughout adulthood.

If you have an occupational therapist, or if your child attends a SEN school, they may be able to provide ideas on toilet training. Also, your local NHS continence service can offer advice and experience, and may be able to supply practical items, such as nappies and pads. Ask your epilepsy nurse or GP for a referral to your local NHS-run service.

When you're out and about, access to disabled toilets can make life easier. Did you know, there's a universal key for all disabled toilets? It's usually called a RADAR key. Ask your GP or search online, you should be able to buy one quite cheaply.



During or just after a seizure, it's common for children and adults with Dravet Syndrome to experience incontinence. It can be helpful to carry spare clothes, wipes and plastic bags when you're out and about in case of a seizure. Nappies may be provided by the NHS once a child is past the age of three years, but these services can vary across different areas of the UK. You can check with your local authority to see if this service is offered in your area.